Parent-Child Dialogue about Epilepsy and Psychosocial Wellbeing: A Mixed Method Study

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A thesis presented to Dublin City University for the Degree of Doctor of Philosophy (PhD)

By

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Declaration

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List of Abbreviations

AED(s)	Antiepileptic drug(s)
CASP	Critical Appraisal Skills Programme
CATIS	Child Attitude toward Illness Scale
CHEQOL	Health-related Quality of Life in Children with Epilepsy Measure
CND	Chronic Neurological Conditions
CSS	Child Stigma Scale
CWE	Child/Children Living with epilepsy
EEG	Electroencephalogram
EI	Epilepsy Ireland (The Irish Epilepsy Association)
ESES	Electrical Status Epilepticus during Slow-wave Sleep
HARCES	Hague Restrictions in Childhood Epilepsy Scale
HCP(s)	Healthcare professional(s)
HRQoL	Health-related Quality of Life
HSE	Health Service Executive
IBE	International Bureau for Epilepsy
ILAE	International League against Epilepsy
IPES	Impact of Paediatric Epilepsy on the Family Scale
M	Mean
MeSH	Medical Subject Headings
MRI	Magnetic Resonance Imaging

MSA	Measures of Sampling Adequacy
MSPSS	Multidimensional Scale of Perceived Social Support
PCA	Principal Component Analysis
PRCI	Parent Response to Child Illness Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSDQ	Parenting Styles and Dimensions Questionnaire
PSS	Parent Stigma Scale
QoL	Quality of life
RFCP	Revised Family Communication Patterns Instrument
SD	Standard Deviation
SJH/AMNCH	St James's Hospital/Adelaide and Meath National Children's Hospital
SPPC	Self-Perception Profile for Children
SSS	Seizure Severity Scale
SSSCA	Social Support Scale for Children
SUDEP	Sudden Unexpected Death in Epilepsy
TSCUH	Temple Street Children's University Hospital
VNS	Vagus Nerve Stimulation
WHO	World Health Organization

Operational Definitions

Absence Seizures: *Seizures that may make the individual appear as if they are daydreaming. The individual "switches off" for a few seconds and experiences a temporary lapse in awareness.*

Atonic Seizures: *Drop attacks; the individual experiences an abrupt loss of muscle tone (temporary paralysis), and may drop to the ground. In some individuals, only their head suddenly drops.*

Clonic Seizures: *The individual experiences rhythmic jerking movements of the arms and legs.*

Complex Partial Seizures: *These seizures may manifest as automatisms (such as lip smacking, picking at clothes, fumbling) or verbal/emotional outbursts. Individuals who experience these types of partial seizures experience a loss of awareness and may wander or stare blankly.*

Epilepsy: Fisher et al. (2014. p.477):

Epilepsy is a disease of the brain defined by any of the following conditions:

1) *At least two unprovoked (or reflex) seizures occurring >24 hours apart*
2) *One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years*
3) *Diagnosis of an epilepsy syndrome*

ESES: Nickels & Wirrell (2008, p.50):

An electroencephalographic pattern showing significant activation of epileptiform discharges in sleep.

Monotherapy: *A form of epilepsy treatment that involves the person with epilepsy taking one type of anti-epileptic drug (generally daily or bi-daily).*

Myoclonic Seizures: *These seizure types manifest as extremely brief shock-like jerks/twitches of a muscle or group of muscles; during such seizures, the individual will usually be awake and be able to think clearly.*

Nuclear Family: *In the present study, the nuclear family is defined as the child's immediately family group consisting of the child with epilepsy, his/her parent(s) and sibling(s).*

Polytherapy: *A form of epilepsy treatment that involves the person with epilepsy taking two or more types of anti-epileptic drugs (generally daily or bi-daily).*

Seizure: Fisher et al. (2014, p.476):
A transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain

Simple Partial Seizures: *Partial seizures can manifest as motor seizures, sensory seizures, autonomic seizures or psychic seizures Individuals who experience simple partial seizure types are fully awake, alert and able to interact throughout the seizure.*

Tonic Seizures: *The individual's arms or legs make sudden stiffening movements; consciousness is usually preserved.*

Tonic-Clonic Seizures: *This type of seizure involves loss of consciousness and consists of a tonic phase where the patient's muscles contract forcefully (i.e. the muscles become tightened and clenched) and a clonic phase where the patient's muscles shake or jerk rhythmically*

and uncontrollably, the eyes roll and the face becomes contorted. Following this type of seizure, the patient generally falls into an unresponsive, exhausted sleep that can last anywhere from a few minutes to a few hours.

Vagus Nerve Stimulation: *A technique used to treat epilepsy that involves the implantation of a device similar to a pacemaker that generates and sends regular, mild pulses of electrical energy to the brain via the vagus nerve. Vagus Nerve Stimulation (VNS) is generally not utilised as a mono-therapy to treat epilepsy but rather acts as an adjunctive therapy (i.e. it is used to compliment drug therapy).*

Abstract

Parent-Child Dialogue about Epilepsy and Psychosocial Wellbeing:

A Mixed-Method Study

Stephanie O' Toole

Background: Epilepsy is one of the most common neurological conditions occurring in childhood. However, the consequences of epilepsy extend beyond seizures to include psychosocial effects interfering with the child's social experiences, quality of life (QOL), and family relations. One particular challenge children living with epilepsy (CWE) and their parents face is the presence, or fear, of societal epilepsy-related stigma, which can sometimes limit family discussions about epilepsy. However, little is known about epilepsy-related dialogue between CWE and their parents.

Aims: This study aims to explore CWE's and parents' experiences of talking about epilepsy together, and the relationship between epilepsy-related communication and a number of demographic, clinical and psychosocial variables.

Methods: A systematic review of available evidence relating to epilepsy-related communication in families living with childhood epilepsy was conducted. Following this, a sequential exploratory mixed-method design was employed involving two phases; 1) qualitative interviews with 29 CWE and 33 parents, and 2) cross sectional surveys completed by 47 CWE and 72 parents.

Results: Integrative findings revealed that CWE and their parents experience many challenges and facilitators to dialoguing about epilepsy, including; condition visibility, epilepsy-related knowledge, fear of causing worry, quest for normalcy, CWE desire for autonomy and parent's desire to protect, and epilepsy-related attitudes. Closed epilepsy-related communication was associated with poorer psychosocial outcomes for CWE and their parents, including; greater perceived-stigma, poorer illness-attitudes, negative self-perceptions, less social support, and poorer QOL. Conversely, open epilepsy-related communication was associated with positive psychosocial wellbeing.

Conclusions: This study contributes significantly to the under-researched area of parent-child epilepsy-related communication. The findings provide valuable information surrounding the contextual factors influencing CWE and parents epilepsy-related dialogue, and the impact of this communication on CWE's and parents' wellbeing. Family-based communication interventions should endeavour to increase epilepsy-related knowledge and CWE autonomy in order to enhance effective parent-child dialogue about epilepsy.

Chapter 1: Introduction

1.0 Introduction to the Present Study

This chapter introduces the prevalence, aetiology, epidemiology, and consequences of childhood epilepsy; family adaptation to childhood epilepsy; the importance of parent-child communication in the lives of children with epilepsy (CWE) and their families; and the rationale for the present study.

1.1 Epilepsy and the Consequences of Epilepsy in Childhood

An essential characteristic of the epidemiology of epilepsy is that it is commonly developed during childhood or adolescence, although epilepsy can become apparent at any stage of a person's life (Cowan, 2002; Szaflarski, Meckler, Privitera, & Szaflarski 2006). Epilepsy is thought to affect approximately 5 cases per 1,000 children and young people, globally, every year (Cowan, 2002). The most recently available Irish statistics estimate that between 8.3 – 9 per 1000 persons 5 years and older in Ireland are being treated for epilepsy using anti-epileptic drugs (AEDs) (Linehan et al., 2010), however, due to the lack of an Irish clinical register for childhood epilepsy and the difficulty and ambiguity surrounding diagnosis, it is thought that this estimation could be undervalued (Linehan et al., 2010; Angus-Leppan, 2008).

Epilepsy is a diverse set of disorders of the brain characterized by a tendency to generate epileptic seizures (Fisher et al., 2005). An epileptic seizure is an interruption of normal brain function due to an abnormal excessive or synchronous electrical activity in the brain (Fisher et al., 2005). Epilepsy comprises a range of variable neurological disorders, characterized by similarly variable elements, including; aetiology, anatomy, age of onset, severity, chronicity, prognosis, and precipitating factors at play. Due to the varying manifestation of the condition, it can be complex to define epilepsy. The Commission on Classification and Terminology of the International League against Epilepsy (ILAE) have recently defined epilepsy as a disease of the brain defined by any of the following conditions; (1) at least two unprovoked (or reflex) seizures occurring more than twenty four hours apart, (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years, and (3) diagnosis of an epilepsy syndrome (Fisher et al., 2014).

The incidence of epilepsy has a bimodal distribution, with the risk of epilepsy peaking during infancy and old age (Asconapé, 2010). Seizures are inclined to begin between early infancy and

late adolescence; however the prevalence for epilepsy also increases for those over the age of 65. Lifetime prevalence of epilepsy is high as up to 70% of individuals can remain successfully seizure-free when treated with AEDs (Asconapé, 2010). Although the majority of individuals with epilepsy are able to live fully functioning lives once a suitable treatment or medication is uncovered, the mortality rate in people with epilepsy is still higher than that in the general population (Cross, 2011). Common causes of death include; status epilepticus (one continuous seizure lasting longer than 5 minutes or recurrent seizures without regaining consciousness in between), seizure trauma, and Sudden Unexpected Death in Epilepsy (SUDEP) (Cross, 2011). Comorbidities such as depression and anxiety disorders are also more commonly found in conjunction with epilepsy (Tellez-Zenteno, Patten, Jetté, Williams, & Wiebe, 2007).

The neurological, cognitive, psychological, and psychosocial consequences of epilepsy are vast at all stages of life; however, epilepsy can have particular social ramifications for children and adolescents. These ramifications can usually be attributed to factors such as the severity of the epilepsy, the age at which it initially occurred and, perhaps most importantly, the visibility of the condition (Solomon & McHale, 2012). In addition, behavioural problems present in as many as 33% of CWE. It is thought that this high rate may be attributed to increased anxiety levels related to co-dependency issues in adolescence and the fear of possible side effects of AEDs (Solomon & McHale, 2012).

In order to gain an understanding of the visibility of particular epilepsies, it is important to first examine the different types of seizures that people with epilepsy can experience. Localized (partial) seizures pertaining to one area of the brain can be divided further into simple partial seizures, where consciousness remains, and complex partial seizures, where there is a loss of consciousness. Complex partial seizures by their nature can become generalized whereby electrical activity spreads to other regions of the brain. In this instance there can be a range of seizures, including; absence, tonic, clonic, tonic-clonic, myoclonic, and atonic seizures. Absence seizures, commonly occurring in forms of childhood epilepsy, are characterized by a brief loss in consciousness without any interruptions or signs. For this reason, absence seizures can often be misinterpreted as daydreaming or inattentiveness in a child if one is unaware of their diagnosis (Solomon & McHale, 2012). Tonic seizures involve a rapid stiffening of the muscles, which may result in the person falling. Clonic seizures involve an abrupt jerking of the limbs. In the case of tonic-clonic seizures, an individual will experience a ‘tonic’ stiffness followed by a ‘clonic’ jerking state. Finally, an atonic seizure involves a loss of muscle tone, again often resulting in a fall for the individual if standing up. Aside from these generalized seizure types,

minor non-convulsive seizures can occur. Such seizures usually manifest with specific behaviours such as blinking, smacking lips or chewing, and can sometimes negatively affect the production of speech (Berg et al., 2010).

Establishing an epilepsy diagnosis is of vital importance to CWE and can have major implications for their health, daily living, and social interactions (Angus-Leppan, 2008). Traditionally, epilepsy is diagnosed via consultation at a neurology clinic, taking into account seizure reports, electroencephalography (EEG) monitoring, and neuro-imaging. EEG monitoring is one of the greatest indicators for a formative diagnosis (Angus-Leppan, 2008). However, Linehan et al. (2010) have recognised a distinct lack of services available to cope with the demand for epileptic diagnosis across the European region and particularly in Ireland where we are largely underserved by the number of paediatric neurologists nationwide. A diagnosis of epilepsy is of great significance as it often represents the first step for CWE and their families to begin adapting to living with the condition (Angus-Leppan, 2008).

1.2 Family Adaptation to Childhood Epilepsy

As with a wide array of chronic neurological childhood illnesses, the impact of childhood epilepsy is not only profoundly significant for the child, but also places a large burden on the child's immediate family (Herzer et al., 2010; Eccleston, Palermo, Fisher, & Law, 2012). Family adaptation in the context of childhood epilepsy refers to how well the family unit functions as a whole in light of the condition (Austin, 1988). A diagnosis of childhood epilepsy can place unprecedented stress on the family, acting as a "stressor" which detrimentally affects the family unit. Disruptions in interfamilial relationships are a significant determinant in the quality of life of any young person, but especially in the case of a young person managing a chronic illness such as epilepsy (Herzer et al., 2010). Previous research has attempted to document the effect of specific family behaviours on the psychosocial well-being of the chronically-ill child (Anthony, Gil, & Schanberg, 2003; Drotar, 1997; McCubbin et al., 1983). However, it is also pertinent to examine the effect that childhood chronic illness in the family can have on family members. Studies investigating these effects suggest that common psychosocial problems which can arise for family members include; stigmatization (Carlton-Ford, Miller, Nealeigh, & Sanchez, 1997), stress (Mims, 1997), psychiatric morbidity (Hoare, 1984; Kugoh & Hosokawa, 1991), poor self-esteem (Austin, 1988), and limited social participation (Thomas & Bindu, 1999; Thompson & Upton, 1992).

The presence of childhood epilepsy can have particular ramifications for parents of CWE. It is essential to understand how parents of CWE adapt to their child's epilepsy, as child adaptation and parent adaptation are intrinsically linked (Modi, 2009). For parents, a diagnosis of epilepsy can bring forth feelings of their child always being different from others, or "the loss of a perfect child" (Ellis, Upton, & Thompson, 2000). As parents search for a cause or explanation for their child's epilepsy, they may focus on attributing the blame to themselves and harbour feelings of guilt in relation to the diagnosis (Ellis et al., 2000). Additionally, prevalence of stress in parents of CWE is markedly higher than that of the general parenting population (Duffy, 2011). When faced with the diagnosis of epilepsy, Duffy (2011) identified the dominant areas of stress for parents as the following; worry about the child, family relationships, need for information, communication, external support, and finances.

Parents of CWE live with many fears and concerns surrounding the uncertainty of their child's condition (Austin et al., 2008). This prevailing uncertainty, combined with the higher stress levels normally found in this population, can result in a reduced ability to cope (Duffy, 2011). Effective coping strategies have been identified as a key behaviour essential to maintaining family functioning during the possible progression of the condition (Ellis et al., 2000). It has been previously demonstrated that effective coping strategies are better facilitated by families with a positive approach to the child's epilepsy, with more negative attitudes resulting in maladaptive behaviours, both from parents and CWE (Duffy, 2011). In an investigation into parent and child attitudes surrounding epilepsy, VanStraten and Ng (2012) found that 20% of parents' interviewed reported a sense of helplessness in response to their child's condition. However, both parents and CWE found it overwhelmingly helpful to spend time with other people living with epilepsy. These interactions reduced feelings of differentness from a CWE perspective (VanStraten & Ng, 2012). Perceived differentness and the "burden of the diagnosis" may cause CWE to self-evaluate differently in a social context or become defined by their diagnosis (Baker, Brooks, Buck, & Jacoby, 2000). As CWE's and parents' attitudes towards epilepsy are fundamental factors in their adaptation to the condition, it is imperative to investigate how these attitudes are formed whilst learning to live with epilepsy.

A child's perception of social support, and most notably family support, can be hugely influential in their successful adaptation to the illness following diagnosis. It is thought that the maintenance of family cohesion could also aid in reducing the amount of stress placed on a parent or CWE and help to effectively maintain family relationships (Duffy, 2011). As with any chronic illness, a major point of concern for parents of CWE is the issue of self-management.

Family cohesion and family attention to self-reliance have been shown to increase a sense of autonomy in young children, leading to better outcomes (Rosland, Heisler, & Piette, 2012). Higher social supports from the family, both practical and emotional, have been strongly linked to improved self-management behaviours in children with chronic illness (Rosland et al., 2012). In the case of epilepsy, practical support can include helping with familiar daily routines, such as changes in eating patterns (attributable to the ketogenic diet) or, in the case of older adolescents, support through any restriction on their ability to participate in peer activities. Emotional support may include helping CWE to combat any disruption the condition may cause to their self-perception, with such support particularly relevant in the case of perceived epilepsy-related stigma (Charyton, Elliott, Lu, & Moore, 2009). Family behaviours such as the provision of family support and family communication are of particular importance in chronic illnesses that require ongoing self-management (Rosland et al., 2012); epilepsy falls within this category.

1.3 The Importance of Parent-Child Communication

A child's communication patterns within the home are largely based upon their surrounding family system (Stafford & Dainton, 1995). Family systems theory, developed by Bowen (1978), is based on the premise of organisation and interrelatedness, with beliefs that; family systems are composed of interrelated parts (family members), change with one part is linked to change in all others, systems maintain a regular state of balance, and systems maintain periods of both change and stability. From a family systems viewpoint, the presence of a chronic illness in a family member can cause changes within the system that may have ramifications for all other members (Kazak, 1989). This perspective also takes into account the liability for family systems to fluctuate over time according to the presence of stressors, such as a chronic-illness diagnosis or periods of increased condition severity (Cohen, 1999; Patterson & Garwick, 1994).

The presence of stress within a family unit may have significant implications for how family members communicate. Family Stress Theory (McCubbin & Patterson, 1983) posits that families tend to reorganize in response to a family "stressor" according to how the stressful event is perceived by family members. A diagnosis of epilepsy in childhood, or a sudden bout of condition severity, can present a significant stressor for both CWE and their parents. McCubbin & Paterson (1983) state that patterns of communication within the family unit may be altered in order for the family to adapt to life with the presence of this stressor. Rolland's Psychosocial Typology of Illness (1984) provides support for the concept of others viewing a family member's illness as a significant stressor. This typology highlights a "crisis" period at the outset of a chronic illness diagnosis, during which time the family may view a condition as a

significant source of stress (Rolland, 1984). Family communication, particularly parent-child communication, around the time of diagnosis is crucial to children's' and parents' successful adaptation to living with a chronic illness (Kazak, 1989). Indeed, a substantial body of research supports the critical value of parent-child interaction in general, suggesting that direct influence on child development can often be attributed to parental social networks (Steinberg 2001; Holmbeck, 1997; Cochran & Brassard, 1979). Therefore, parent-child interactions in the case of chronically-ill children, and their potential to impact upon a child's ability to cope with their condition, denote a worthy investigation.

Parental figures are known to provide a critical environment for children's development with much family research placing emphasis on the quality of the parent-child relationship (Halpenny, Nixon, & Watson, 2010; Pinquart, 2013; Raudino, Fergusson, & Horwood, 2013). Indeed, parenting is recognised as a significant predictor of children's wellbeing and adjustment (Deater-Deckard & Dunn, 1999). An integral component of the parenting process is effective communication within the parent-child dyad, particularly within families of chronically-ill children. Previous research has pinpointed parent-child communication within these families to play an essential role in; effectively informing and guiding children in relation to their condition (Young, Dixon-Woods, Windridge, & Heney, 2003), encouraging self-efficacy in condition-management (Young et al., 2003), and fostering adherence to medication regimes (DiMatteo, 2004).

The level and form of communication parents and children engage in is largely dependent on the parenting style adopted within the family home. Maccoby and Martin (1983) have defined a number of varying parenting styles which may be adopted; 1) authoritative parenting, in which parents engage in open communication with their child, 2) authoritarian parenting, in which parents engage in low levels of communication with their child, and 3) permissive parenting, often referred to as "lax" or "uninvolved" parenting, in which little value is placed on parent-child communication. Previously, a higher level of authoritarian parenting has been linked to the experiences of chronically-ill children compared to non-chronically-ill children (Nixon, 2012), however, little is known of the direct experiences of CWE and parents of CWE specifically when communicating about epilepsy together.

As parent-child communication about epilepsy may influence the perceptions CWE and parents have surrounding the condition, it is imperative to investigate the ways in which CWE and parents dialogue about epilepsy and the impact of this dialogue on their psychosocial wellbeing.

Though some previous studies have conducted research examining parent-child communication in the context of other chronic illnesses, such as asthma (Evans, Clark, Levison, Levin, & Mellins, 2001), diabetes (Hanna, Juarez, Lenss, & Guthrie, 2003), and sickle-cell disease (Evans, Burlew, & Oler, 1988), no previous studies have sought to explicitly investigate parent-child communication in the context of epilepsy. Furthermore, no studies have sought to access the direct experiences of CWE and their parents, separately, when choosing to communicate, or not, about epilepsy. Though parent-child communication may be implicated as a result of the parenting approach adopted within families, children also play an integral role in the adoption of specific communication behaviours. Parent-child communication is a fundamentally bi-directional process. Thus, it is imperative to not only ascertain how CWE perceive their parents to communicate about epilepsy, but also to examine how CWE choose to communicate with their parents, or not, about their condition.

1.4 Rationale for the Present Study

A gap exists in the research literature investigating the communication strategies employed by CWE and their families surrounding the condition. It is critical to explore parent-child communication strategies surrounding epilepsy in order to further examine the facilitators, barriers, environmental and contextual factors of such discussions, and to inform the design of family-based communication interventions that may alleviate any challenges that CWE and their parents may face when talking about the condition. The present study aims to explore parent-child dialogue about epilepsy from CWE and parent perspectives, and to establish the relationship between epilepsy-related dialogue and CWE's and parents' psychosocial wellbeing.

Prior to the conduct of the present study, a systematic review was conducted to synthesise all available evidence relating to parent-child communication in families living with epilepsy in childhood. The findings of this review, and further rationale for the present study, are detailed in the following chapter.

1.5 Thesis Conspectus

This thesis consists of eleven chapters. *Chapter two* presents a systematic review of the existing evidence on family communication about epilepsy. *Chapter three* presents the mixed methods study design. In *chapter four* the qualitative methods for phase one of this study are detailed. *Chapter five* presents the qualitative findings of the first phase of the study. In *chapter six* the qualitative findings of the study are critically discussed, alongside an outline of how the first

phase of this study contributed to the second quantitative phase. In *chapter seven* the quantitative methods for the second phase of the study are described. *Chapter eight* presents the results of the quantitative phase of the study. In *chapter nine* the quantitative results from phase two are critically discussed. In c*hapter ten*, an integration of the findings from both the qualitative and quantitative phases is presented followed by a critical discussion of the key findings of the mixed-method study. C*hapter eleven* details the present study's original contribution, strengths and limitations, and implications for practice, research, and policy.

Chapter 2: Systematic Review of the Literature

2.0 Introduction

In this chapter a systematic review of empirical evidence on family communication about epilepsy in childhood is presented.

2.1 Systematic Review Background

Extensive research has been conducted on the effect of chronic childhood conditions on family relationships and functioning (Herzer et al., 2010; Årestedt, Persson, & Benzein, 2014; Thompson & Upton, 1992). Epilepsy, unlike many other chronic childhood conditions, is a potentially invisible condition; i.e. – when seizures are controlled, it is not always apparent that a child may have epilepsy (Joachim & Acorn, 2000a). Due to the unique invisible nature of epilepsy and the effect that visibility can have on both children's participation in activities and their rationale behind disclosing or not disclosing their condition to others, a particular emphasis has been placed on the impact of family discussions surrounding epilepsy in this review.

Previous research in the area of child adjustment to chronic illness has identified parents as critical figures for the successful adaptation of effective coping strategies by children when learning to deal with their condition (Drotar, 1997; Compas, Jaser, Dunn, & Rodriguez, 2012; Cole & Reiss, 2013). Although fostering open communication with young people with chronic illness is known to be problematic (Young et al., 2003), the crucial role of parents as communicators has also been demonstrated (Drotar, 1997; Stille, Primack, McLaughlin, & Wasserman, 2007). Young et al. (2003) found that young people with chronic illness sought information relating to their condition from those with whom they had a close and longstanding relationship. Children with chronic illness often welcomed this parent-child communication, identifying their parents as effective communication buffers (shielding them from the burden of answering questions relating to their condition), communication brokers (tailoring information pertaining to their condition for their understanding) and key facilitators of communication with healthcare professionals (Young et al., 2003).

Despite these positive reinforcements for facilitating family communication surrounding childhood illness, parent child dialogue pertaining to epilepsy may present a more challenging task. Epilepsy is a condition with an ancient and well-documented association with stigma (Schneider & Conrad, 1980; Baker et al., 2000; Morrell, 2002; Fisher et al., 2000). People with stigmatized illnesses often avoid communicating about their condition (Berger, Wagner, &

Baker, 2005). Secrecy and social withdrawal are key examples of how epilepsy-related stigma has been demonstrated to infringe on the quality of life of people living with epilepsy (Jacoby, Snape, & Baker, 2005). From a paediatric perspective, epilepsy-related stigma has come to the fore of the research literature surrounding quality of life in epilepsy as a key determinant of the way in which CWE perceive their condition (Schneider & Conrad, 1980). The World Health Organisation (WHO), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) have identified the reduction of epilepsy-related stigma as a key focus in their "Bringing Epilepsy Out of the Shadows" International campaign, a movement aimed at heightening the global social-acceptability of the disorder (Reynolds, 2000). This campaign remains pertinent today, with the launch of an International Epilepsy Day, a special annual event aimed at raising awareness about epilepsy and reducing the misconceptions, stigmatisation and discrimination of epilepsy globally (International Bureau for Epilepsy, 2015).

Despite this recognition of stigma as a burden for CWE, little is known of how it may impact upon families living with childhood epilepsy. Qualitative investigations with CWE and their parents have revealed that this stigma and felt need-for-secrecy is often more burdensome than the physical manifestations of seizures themselves (Jacoby & Austin, 2007). A number of reasons have been suggested for familial silence surrounding epilepsy. Often, parents' fear of their child being viewed as different alongside their negative perceptions of seizures and epilepsy-related stigma can cause them to not discuss epilepsy with their child, thus relaying to CWE that epilepsy is something that should not be talked about (Schneider & Conrad, 1980). This silence can itself be a child's first encounter with stigma (Scambler & Hopkins, 1986). Jacoby and Austin (2007) have identified the key role of parents in their children's lives as "stigma-coaches", encouraging their child to view his/her condition through their perceptions, beliefs and attitudes pertaining to it (Jacoby & Austin, 2007). The consequences of silence surrounding epilepsy within the family environment are vast, including child exclusivity and isolation fuelled by imposed restrictions of social activities (Austin et al., 2008). The WHO International Classification of Functioning, Disability and Health, developed in 2001, emphasises the role that environmental and personal factors may play in hampering a child's engagement with his/her chronic condition, such as, in this case, communication about epilepsy (WHO, 2001). The examination of familial communication practices surrounding epilepsy is therefore of critical importance.

2.2 Systematic Review Aims

The aim of the following review was to systematically examine the evidence on communication in families living with epilepsy in childhood, particularly parent and child discussions surrounding epilepsy and epilepsy-related issues within the context of the family home.

The specific questions of the review were;

1. What are the communication strategies employed by families living with childhood epilepsy?
2. What are the facilitators and barriers for families to communicating about epilepsy, from both a parent and child perspective?
3. What challenges do families living with epilepsy in childhood face when communicating about epilepsy, from both a parent and child perspective?
4. What impact does communication about epilepsy have on families living with epilepsy in childhood?

2.3 Systematic Review Method

This systematic review was conducted and reported in accordance with the guidelines published on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009).

2.3.1 Search strategy and study selection criteria

A search for potentially eligible papers up to March 2015 was undertaken across six databases; PubMed, MedLine, Web of Science, PsycInfo, CINAHL and SCOPUS. A combination of controlled vocabulary from databases (e.g., MESH) and free text words were chosen to reflect the review's focus on epilepsy: family, parents, young people, adolescents, children, communication, dialogue, talks and conversations. The final search strategy utilised is outlined in Table 2.1.

Table 2.1: ***Systematic Review: Database Search Strategy***

Databases: PubMed, MedLine, Web of Science, PsycInfo, CINAHL, SCOPUS
Search strategy:
1. Epilepsy
2. epilept*
3. epileps*
4. seizure disorder*
5. 1 or 2 or 3 or 4
6. Family
7. famili*
8. parent*
9. child*
10. adolescen*
11. young*
12. young person*
13. 6 or 7 or 8 or 9 or 10 or 11 or 12
14. communicat*
15. communication*
16. dialogue
17. talk*
18. conversat*
19. conversing
20. 14 or 15 or 16 or 17 or 18 or 19
21. 5 and 13 and 20
Final search strategy: "epilepsy OR epilept* OR epileps* OR seizure disorder* AND family OR famili* OR parent* OR child* OR adolescen* OR young* OR young person* AND communicat* OR communication* OR dialogue OR talk* OR conversat* OR conversing"

The pre-specified inclusion and exclusion criteria for the review are shown in Table 2.2. These criteria were mapped according to publication type, study design, population, and the study's primary focus. Reference lists of all eligible research studies and any relevant published reviews were also screened for relevant papers.

Table 2.2: ***Systematic Review: Inclusion and exclusion criteria***

	Inclusion criteria	Exclusion criteria
Publication type	Papers published in the English language	Books, book chapters, opinion pieces, editorials, letters, systematic reviews, dissertations/theses
Study design	Empirical studies implementing either a qualitative, quantitative or mixed methods approach	
Population	1) Children with epilepsy (0 – 18 years) 2) Parents of children with epilepsy 3) Children with epilepsy and their parents	1) Children with epilepsy who also had intellectual disabilities 2) Children with epilepsy who also had a communicative disorder
Study focus	1) Family communication surrounding epilepsy 2) Parent and child discussions about epilepsy and epilepsy related issues	1) The cause of epilepsy only 2) Prognosis only 3) Medication and treatment only 4) Peer communication only 5) Healthcare communication only 6) Chronic illness only - no report of epilepsy specific data

2.3.2 Methods of the review

A number of stages were employed in the screening of papers against the inclusion and exclusion criteria to identify studies eligible for inclusion in the review. First, the electronic search across the six databases was completed. Following this any duplicate papers were identified and removed. The remaining papers underwent a two-stage screening process. In the first stage, the titles and abstracts of all papers were screened by two review authors. In the second stage of screening, the full texts of potentially eligible papers were retrieved and reviewed independently by two review authors for eligibility. Two further reviewers resolved any discrepancies through discussion. Reasons for excluding studies at all stages were noted (see Figure 2.1).

2.3.3 Data extraction and synthesis

Results were tabulated to capture the key data extracted from the included studies. The following methodological information was extracted for each study: author, year and country of origin; study aim/objective; study design; data collection method (including any measures/instruments); sample; recruitment source; and key findings related to family communication about epilepsy (see Appendix A). All data were extracted independently by two reviewers and cross-checked by two other reviewers for accuracy with any discrepancies

resolved through discussion. Due to methodological heterogeneity, a narrative-analysis was conducted across all findings.

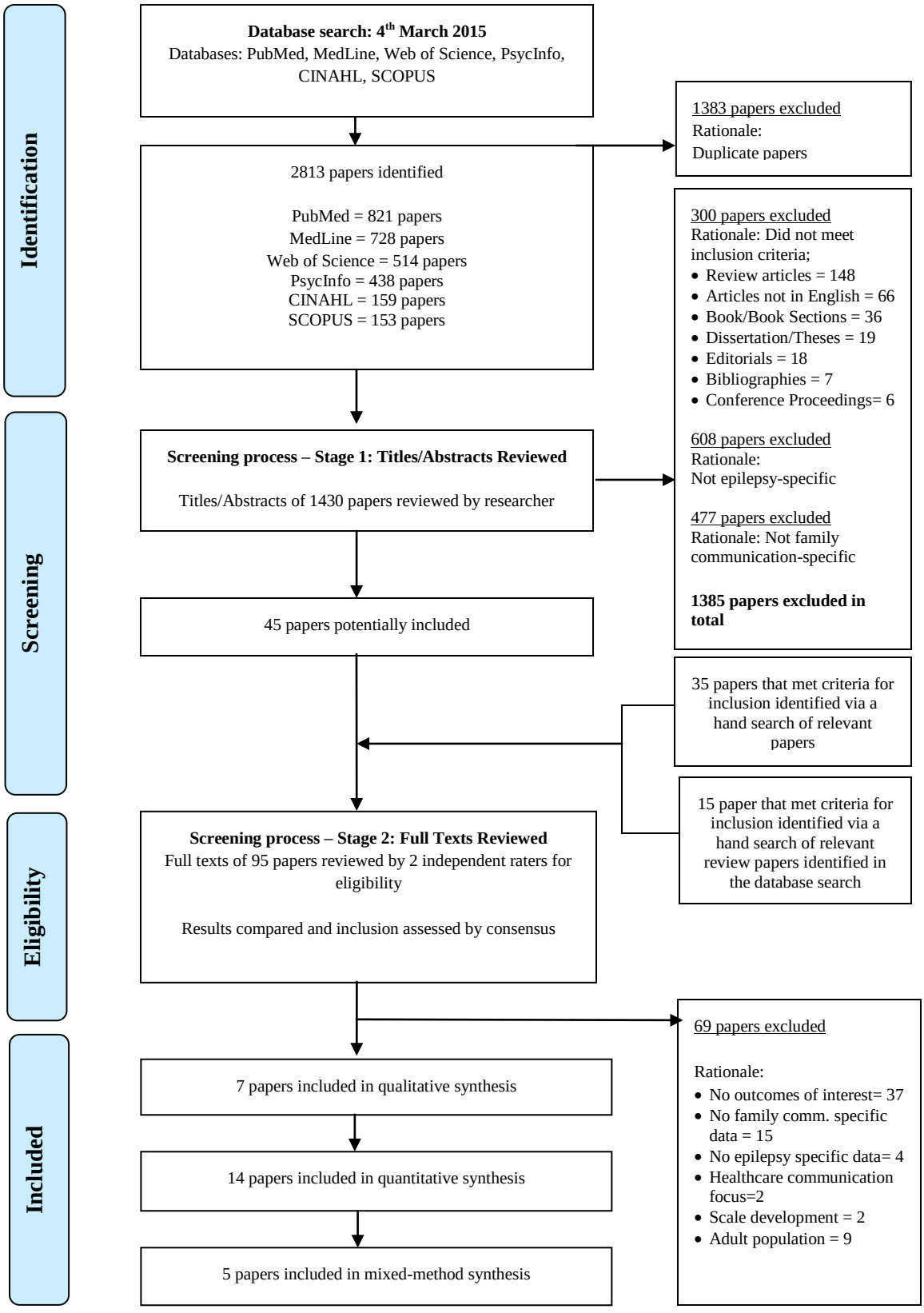
2.3.4 Critical appraisal

The quality of included studies was assessed independently by two reviewers with two other reviewers resolving any disagreements by discussion and consensus. For qualitative studies, the CASP (Critical Appraisal Skills Programme) tool developed by the Public Health Resource Unit, Oxford (2006) was used to assess each study according to the criteria presented in Table 2.3 with a rating of yes, no, or can't tell (Public Health Resource Unit, 2006). For quantitative and mixed method studies, a modified version of the Quality of Life Index designed by Tsimicalis, Stinson, and Stevens (2005) was used (see Table 2.4). This tool assesses quality according to the parameters; study design, participants and recruitment, comparison group, number of participants, and instrument psychometric properties/outcome measurement.

2.4 Systematic Review Findings

A PRISMA flow diagram depicting stages of the screening and selection process is presented in Figure 2.1. The search strategy yielded 2813 papers for screening. Of 1430 papers retained after duplicates were removed, 1383 were excluded because they did not meet the inclusion criteria. Forty-five papers were identified as potentially eligible for inclusion. A further 35 papers were added following manual screening of titles and abstracts of the bibliographies of these potentially included papers. Additionally, a further 15 papers were added following manual screening of the bibliographies of review papers yielded within the database search. This resulted in screening 95 full text papers; 69 of which were excluded (See Figure 2.1). A total of 26 papers were deemed eligible for inclusion in the review.

Figure 2.1: ***Systematic Review: Flow of identification and selection process (PRISMA)***



2.4.1 Description of included studies

The 26 studies included in the review were published between and 1977 and 2013 and involved a total of 4850 participants. Eighteen studies were published over ten years ago (Hightower, Carmon, & Minick, 2002; McEwan, Espie, Metcalfe, Brodie, & Wilson, 2004; Mulder & Suurmeijer, 1977; Ronen, Rosenbaum, Law, & Streiner, 1999; Austin, McNelis, Shore, Dunn, & Musick, 2002; Coulter & Koester, 1985; Hanai, 1996; Hoare, 1984; Hoare & Kerley, 1991; Lothman & Pianta, 1993; Stores & Piran, 1978; Ferrari, Matthews, & Barabas, 1983; Hodes, Garralda, Rose, & Schwartz, 1999; Hodgman et al., 1979; Nicholas & Pianta, 1994; Ritchie, 1981; Chavez & Buriel, 1988; Kitamoto et al., 1988). Most studies (n=14) were quantitative in design (Herzer et al., 2010; Coulter & Koester, 1985; Hanai, 1996; Hoare, 1984; Hoare & Kerley, 1991; Lothman & Pianta, 1993; Stores & Piran, 1978; Ferrari et al., 1983; Hodes et al., 1999; Ritchie, 1981; Chavez & Buriel, 1988; Kitamoto et al., 1988, Hirfanoglu et al., 2009; Tzoufi et al., 2005), 7 studies were qualitative (Hightower et al., 2002; McEwan et al., 2004; Mulder & Suurmeijer, 1977; Ronen et al., 1999; McNelis, Buelow, Myers, & Johnson, 2007; Moffat, Dorris, Connor, & Espie, 2009; Mu, 2008), and 5 implemented a mixed method design (Austin et al., 2002; Hodgman et al., 1979; Nicholas & Pianta, 1994; Tzoufi et al., 2005; Jantzen et al., 2009). The studies were conducted in the United States (n = 10), the United Kingdom (n = 6), Taiwan (n = 2), Japan (n = 2), Germany (n = 1), Australia (n = 1), Greece (n = 1), Netherlands (n = 1), Canada (n = 1) and Turkey (n = 1).

Over half of the studies (n = 14) included child and parent populations (Mulder & Suurmeijer, 1977; Ronen et al., 1999; Austin et al., 2002; Lothman & Pianta, 1993; Ferrari et al., 1983; Hodes et al., 1999; Hodgman et al., 1979; Nicholas & Pianta, 1994; Ritchie, 1981; Chavez & Buriel, 1988; Kitamoto et al., 1988; McNelis et al., 2007; Hirfanoglu et al., 2009; Jantzen et al., 2009), 9 studies involved parent populations (Herzer et al., 2010; Coulter & Koester, 1985; Hanai, 1996; Hoare, 1984; Hoare & Kerley, 1991; Stores & Piran, 1978; Mu, 2008; Tzoufi et al., 2005; Mu & Chang, 2010), and 3 studies included child/young person populations (ranging from 7 – 18 years) (Hightower et al., 2002; McEwan et al., 2004; Moffat et al., 2009). Overall, studies ranged in participant numbers from 8 to 2152.

Fourteen studies identified family communication about epilepsy as a primary focus (Herzer et al., 2010; Mulder & Suurmeijer, 1977; Austin et al., 2002; Lothman & Pianta, 1993; Ferrari et al., 1983; Hodes et al., 1999; Ritchie, 1981; Chavez & Buriel, 1988; Kitamoto et al., 1988; Mu, 2008; Hirfanoglu et al., 2009; Tzoufi et al., 2005; Jantzen et al., 2009; Mu & Chang, 2010). For the remaining 12 studies, family communication about epilepsy was not a primary focus but

emerged as a subordinate subject matter. As a consequence, while all studies examined either the perspectives of CWE and/or their parents, the specific aims and objectives of the studies varied. For instance, 14 studies addressed differences in family functioning (ranging from family relationships, interactions and adjustment/coping strategies) (Herzer et al., 2010; Mulder & Suurmeijer, 1977; Austin et al., 2002; Lothman & Pianta, 1993; Ferrari et al., 1983; Hodes et al., 1999; Ritchie, 1981; Chavez & Buriel, 1988; Kitamoto et al., 1988; Mu, 2008; Hirfanoglu et al., 2009; Tzoufi et al., 2005; Jantzen et al., 2009; Mu & Chang, 2010), 3 studies examined dependency in CWE (Hoare, 1984; Hoare & Kerley, 1991; Ferrari et al., 1983), 4 studies investigated the impact of childhood epilepsy on quality of life (McEwan et al., 2004; Ronen et al, 1999; Hanai, 1996; Moffat et al., 2009), 2 studies investigated the behavioural characteristics of CWE (Hodgman et al., 1979; Nicholas & Pianta, 1994), and 2 studies investigated child and parent concerns related to epilepsy (Coulter & Koester, 1985; McNelis et al., 2007). One study examined children's self-reported experiences of their epilepsy (Hightower et al., 2002).

2.4.2 Methodological quality of included studies

Missing information was a common problem affecting study quality assessment, which often accounted for many 'can't tell' ratings (Table 2.3). Use of the CASP tool deemed the 7 qualitative studies included in this review to be of a moderately high quality (Public Health Resource Unit, 2006). For the 14 quantitative and 5 mixed method studies included in the review, the total mean quality index score calculated using an adapted version of the Quality of Life Index Appraisal tool (Tsimicalis et al., 2005) was 7.2 out of 15, with scores ranging from 1 – 11 (Table 2.4).

A number of methodological issues arose within the papers included in this review. There was a wide variation in the sample size of quantitative studies with 5 out of 19 papers having a sample size of <50 (Austin et al., 2002; Coulter & Koester, 1985; Ferrari et al., 1983; Hodes et al., 1999; Hodgman et al., 1979). This raises questions about whether these studies were sufficiently powered to detect significant findings. In a number of studies, key clinical characteristics that might potentially influence findings were not reported. For example, seizure type and degree of seizure control of child participants was not reported in the majority of studies. Furthermore, information on key sociodemographic characteristics was largely absent. Parent education levels were only reported in five studies. Socioeconomic status was only reported in six studies. It is also important to note that thirteen of the studies did not include a comparison group and where comparison groups were included there was wide variability in their composition; three

studies included a comparison group (children with other chronic illnesses, parent proxy-report), four studies included a reference sample and six studies were conducted with a healthy, age appropriate comparison group. Due to limited reporting within the majority of the studies included in this review, comment is not possible on a number of methodological aspects (e.g., selection bias and response rates). Several sources of methodological heterogeneity were noted; including, study design, samples that differed in terms of clinical and sociodemographic characteristics, outcome variables, and outcome measures reported.

Table 2.3: ***Systematic Review: Critical Appraisal of Qualitative Studies***

Author (year)	Clear statement of aims	Appropriate qualitative methodology	Appropriate research design	Appropriate recruitment strategy	Appropriate data collection method	Researcher-participant relationship considered	Ethical issues considered	Rigorous data analysis	Clear statement of findings	Valuable research
Hightower, Carmon & Minick (2002)	Yes	Yes	Can't tell	Can't tell	Yes	No	Can't tell	Can't tell	Yes	Yes
McEwan et al. (2004)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
McNelis, Buelow, Myers & Johnson (2007)	Yes	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Can't tell	Yes	Yes
Moffat, Dorris, Connor & Espie (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mu (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mulder & Suurmeijer (1977)	No	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Can't tell
Ronen, Rosenbaum, Law & Streiner (1999)	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Yes	Yes

Table 2.4: ***Systematic Review: Critical Appraisal of Quantitative Studies***

Author (year)	Study design[1]	Participants and recruitment[2]	Comparison group[3]	Number of participants[4]	Family communication instruments[5]	Total
Austin et al. (2002)	0	0	0	1	2	**3**
Chavez & Buriel (1988)	0	0	3	3	1	**7**
Coulter & Koester (1985)	0	2	1	1	0	**4**
Ferrari, Matthews & Barabas (1983)	0	0	3	1	0	**4**
Hanai (1996)	0	1	1	3	0	**5**
Herzer et al. (2010)	1	0	3	3	2	**9**
Hirfanoglu et al. (2009)	0	0	0	3	0	**3**
Hoare (1984)	0	0	2	3	2	**7**
Hoare & Kerley (1991)	1	2	3	3	1	**10**
Hodes, Garralda, Rose, Schwartz (1999)	0	3	3	1	0	**7**
Hodgman et al. (1979)	0	0	0	1	0	**1**
Jantzen et al. (2009)	3	3	2	3	0	**11**

[1] Study design: 0=Survey or do not report; 1=Cross-sectional (explicitly stated); 2=Retrospective or mixed design (explicitly stated); 3=Longitudinal prospective design (explicitly stated)

[2] Participants and recruitment: 0=More than two criteria missing; 1=Two criteria missing; 2=Minimal description of at least four criteria; 3=Description of the population (1), and eligibility criteria for participants (2), precise details of the recruitment process (3), accounted for the numbers recruited (4), and lost to follow-up (5)

[3] Comparison group: 0=No comparison group; 1=Other comparison group (i.e. Adult epilepsy population, children with other chronic illnesses, parent-report); 2=Reference sample; 3=Healthy, age-appropriate comparison

[4] Number of participants: 0=Did not report; 1=N<50; 2=N=50-100; 3=N>100

[5] Family communication instruments: 0=Investigator constructed clinical rating of family communication with no psychometric properties reported or family communication measured as a sub-component of another domain. Use of self-report or proxy-report; 1=Psychometric properties of instruments, or sub-scales, not reported or reported as inadequate for measuring family communication. Use of self-report or proxy-report; 2=Some weak psychometric properties reported for generic and/or disease-specific family communication measures or sub-components of measures. Use of self-report; 3=Report of psychometrically sound generic and/or disease-specific family communication measures. Use of self-report.

Author (year)	Study design[6]	Participants and recruitment[7]	Comparison group[8]	Number of participants[9]	Family communication instruments[10]	Total
Kitamoto et al. (1988)	0	0	2	3	1	**6**
Lothman & Pianta (1993)	0	0	0	3	1	**4**
Mu & Chang (2010)	3	2	0	2	2	**9**
Nicholas & Pianta (1994)	0	0	0	3	0	**3**
Ritchie (1981)	1	0	3	1	0	**5**
Stores & Piran (1978)	0	1	2	2	2	**7**
Tzoufi et al. (2005)	0	2	1	2	0	**5**

[6] Study design: 0=Survey or do not report; 1=Cross-sectional (explicitly stated); 2=Retrospective or mixed design (explicitly stated); 3=Longitudinal prospective design (explicitly stated)

[7] Participants and recruitment: 0=More than two criteria missing; 1=Two criteria missing; 2=Minimal description of at least four criteria; 3=Description of the population (1), and eligibility criteria for participants (2), precise details of the recruitment process (3), accounted for the numbers recruited (4), and lost to follow-up (5)

[8] Comparison group: 0=No comparison group; 1=Other comparison group (i.e. Adult epilepsy population, children with other chronic illnesses, parent-report); 2=Reference sample; 3=Healthy, age-appropriate comparison

[9] Number of participants: 0=Did not report; 1=N<50; 2=N=50-100; 3=N>100

[10] Family communication instruments: 0=Investigator constructed clinical rating of family communication with no psychometric properties reported or family communication measured as a sub-component of another domain. Use of self-report or proxy-report; 1=Psychometric properties of instruments, or sub-scales, not reported or reported as inadequate for measuring family communication. Use of self-report or proxy-report; 2=Some weak psychometric properties reported for generic and/or disease-specific family communication measures or sub-components of measures. Use of self-report; 3=Report of psychometrically sound generic and/or disease-specific family communication measures. Use of self-report.

2.4.3 What are the communication strategies employed by families living with epilepsy?

A total of 12 studies made reference to the communication strategies employed by families living with childhood epilepsy (Herzer et al., 2010; Mulder & Suurmeijer, 1977; Austin et al., 2002; Hoare, 1984; Hoare & Kerley, 1991; Stores & Piran, 1978; Ferrari et al., 1983; Hodes et al., 1999; Hodgman et al, 1979; Ritchie, 1981; Mu, 2008; Tzoufi et al., 2005). While none of these studies identified the particular communication strategies adopted by families living with childhood epilepsy, they provided insights into the ways families did, or did not, discuss epilepsy and non-epilepsy related issues. Family members of children with chronic neurological conditions (CND) and, specifically, epilepsy were unlikely to discuss their personal problems and less likely to engage in discussions surrounding epilepsy in the home (Tzoufi et al., 2005). In terms of overall family functioning, 23% of families living with childhood epilepsy endorsed unhealthy levels of functioning, a similar level to that of families living with other common pediatric illnesses (Herzer et al., 2010), however, it was found that this level of family functioning could be increased following an intervention designed specifically for families living with epilepsy (Austin et al., 2002). One study reported on factors that might potentially predict the level of communication adopted by families living with epilepsy postulating that better seizure control often resulted in children seeking to speak to their parents or siblings about epilepsy less frequently (Hodgman et al., 1979).

Four studies referred to role changes in families living with epilepsy (Mulder & Suurmeijer, 1977; Hodes et al., 1999; Ritchie, 1981; Mu, 2008). Two studies found a tendency for mothers to take a dominant controlling role both in primarily dealing with the child's epilepsy condition management and speaking about the condition in the home (Mulder & Suurmeijer, 1977; Ritchie, 1981). Mothers' were reported as being more affectionate than fathers, whose attitudes were sometimes viewed as rejecting (Mulder & Suurmeijer, 1977). However, mothers of CWE, in comparison to mothers of children with other chronic illnesses and mothers of healthy children, were found to elicit significantly fewer positive responses to their child in organised play (Chavez & Buriel, 1988). One study found that family members living with childhood epilepsy were more likely to conform to group decision than members of families living without childhood epilepsy (Ritchie, 1981). Another study reported significant emotional over-involvement of mothers to their CWE as compared to other siblings without epilepsy and a near significant trend for mothers to make hostile comments towards their CWE more frequently than their siblings (Hodes et al., 1999). This trend was reinforced in another study, reporting that

mothers tended to scold and punish their child if their child's epilepsy was within five years of diagnosis and their seizures were controlled (Kitamoto et al., 1988).

The view that CWE needed a greater level of care and attention was echoed in another study, despite it being acknowledged by parents that this was often at the expense of the child's siblings (Mulder & Suurmeijer, 1977). However, parents strove to strengthen their parental roles by; establishing a mutually respectful and accepting family environment, encouraging and supporting their child's appropriate behaviour, establishing a reasonable parenting and disciplining style and ensuring appropriate interaction patterns and mutual respect between siblings (Mu, 2008).

Finally, 3 studies found that CWE were significantly more dependent on their parents than children in the general population (Hoare, 1984; Hoare & Kerley, 1991; Stores & Piran, 1978); this finding was particularly salient in boys of secondary-school level (Hoare & Kerley, 1991). Interestingly, in their investigation into the development of appropriate dependency in children with chronic and newly diagnosed epilepsy, compared to children with chronic and newly diagnosed diabetes, Hoare (1984) found that inappropriate dependency is not an invariable accompaniment of chronic disease but is unique to the nature of epilepsy in this case. CWE were shown to be particularly dependent on their parents in terms of how frequently they engaged in communication with them (Hoare & Kerley, 1991; Stores & Piran, 1978).

2.4.4 What are the facilitators and barriers relating to communicating about epilepsy, from both a parent and CWE perspective?

Factors potentially facilitating family communication about epilepsy were not reported upon within the studies included in this review. However, parents highlighted the need to encourage their child to talk to them as a significant concern (Coulter & Koester, 1985).

Seven studies identified barriers that might hinder either parents and/or CWE from talking about the condition within a family context (McEwan et al., 2004; Mulder & Suurmeijer, 1977; Ronen et al., 1999; Hodgman et al., 1979; Moffat et al., 2009; Mu, 2008; Hirfanoglu et al., 2009). For CWE, barriers identified were; parental desire to keep epilepsy a secret (Moffat et al., 2009); parents tendency to deny epilepsy - particularly in the case of poor seizure control (Hodgman et al., 1979); parental overprotection (McEwan et al., 2004); and parents imposing greater restrictions on the CWE than siblings without epilepsy (Moffat et al., 2009). Parental hyper-

vigilance and activity restriction was a key issue throughout the studies. Children/adolescents reported activity limitations and heightened supervision (McEwan et al., 2004; Moffat et al., 2009) and 63.2% of children reported they were bothered by their parents' felt need for supervision (Hirfanoglu et al., 2009). Two studies found that a rise in parental knowledge about epilepsy resulted in a decrease in the level of restrictions imposed on the child (McEwan et al., 2004; Hirfanoglu et al., 2009).

A parental barrier to communicating about epilepsy within the home was the reluctance of parents to use the word "epilepsy" when conversing with their child about his/her condition, due to the perceived negative social connotations attached to epilepsy and a fear of their child being stigmatized outside of the home (Mulder & Suurmeijer, 1977; Ronen et al., 1999; Mu, 2008). This was particularly relevant to family conversations during the first one and a half years following the diagnosis of epilepsy (Mu, 2008). Parents felt that they should not use the word "epilepsy" in order to discourage their child from using this term in social situations (Ronen et al., 1999). One instance was reported in which a parent explicitly told their child not to use the word "epilepsy" (Mulder & Suurmeijer, 1977).

2.4.5 What challenges do families living with epilepsy face when communicating about epilepsy, from both a parent and CWE perspective?

Eight studies reported on challenges families face when conversing about epilepsy and epilepsy related issues (Hightower et al., 2002; Coulter & Koester, 1985; Hanai, 1996; Ferrari et al., 1983; McNelis et al., 2007; Moffat et al., 2009; Hirfanoglu et al., 2009; Mu & Chang, 2010). The main challenges for mothers and fathers included; unwillingness of the child to answer epilepsy-related questions (Hightower et al., 2002), lack of parental knowledge about their child's epilepsy (McNelis et al., 2007), and parents' perceptions of themselves as key role-models in their child's perceptions of epilepsy (McNelis et al., 2007).

Parents faced challenges in creating an emotionally and practically supportive environment for their CWE. One in 5 children reported not having enough support from their own families (Hirfanoglu et al., 2009). In 2 studies, parental concern related to encouraging communication with their child (Coulter & Koester, 1985), maintaining family stability, and encouraging appropriate interactions with the child (Mu & Chang, 2010) were highlighted.

Challenges faced by children were fear of parental worry (Moffat et al., 2009), perceptions of themselves as problematic to the family unit (Ferrari et al., 1983), and children feeling insufficiently informed about their epilepsy (Hanai, 1996; Hirfanoglu et al., 2009). In one study, 20% of parents did not sufficiently inform their children about epilepsy (Hirfanoglu et al., 2009). The more siblings that CWE had, the less knowledge about epilepsy he or she was likely to have (Hirfanoglu et al., 2009). These findings were similar to that of another study investigating the level of explanation parents of CWE provided in relation to the condition – 26% of parents explained epilepsy to their child in detail, 23% of parents explained a little about epilepsy to their child and 31% of parents explained to their child only that seizures occurred (Hanai, 1996).

2.4.6 What impact does communication about epilepsy have on families living with epilepsy in childhood?

The impacts of family communication about epilepsy were observed in 4 studies (Austin et al., 2002; Nicholas & Pianta, 1994; Moffat et al., 2009; Jantzen et al., 2009). Positive impacts of talking about epilepsy for CWE included parents keeping them safe and helping with seizures (Moffat et al., 2009). Mother-child interactions and quality of the parent-child relationship were found to have a positive impact on child competence and independent problem-solving abilities (Lothman & Pianta, 1993; Nicholas & Pianta, 1994). Negative impacts of communication were not reported in any of the studies included in this review.

Two studies assessed the efficacy of interventions aimed at improving the quality of life for CWE and their parents (Austin et al., 2002; Jantzen et al., 2009). Following a psycho-educational family intervention aimed at improving attitudes towards epilepsy and family functioning, Austin et al. (2002) found a notable increase in post-intervention family functioning from the perspective of the child. Similarly, a communication intervention for CWE and their parents resulted in increased child self-management and a greater child-reported ability to explain epilepsy (Jantzen et al., 2009).

2.5 Systematic Review Discussion

The aim of this review was to identify the existing evidence available on the communication strategies employed by families living with childhood epilepsy when talking about epilepsy in the home, the perceived facilitators, barriers and challenges surrounding this communication and the impact of communicating, or not, about epilepsy and epilepsy-related issues. Positive

impacts of talking about epilepsy were identified for CWE, these included; heightened feelings of safety, greater competence and further development of independent problem-solving abilities. No negative impacts of family communication about epilepsy were uncovered within the studies included in this review. No studies reported on the specific communication strategies adopted by families of CWE, however, evidence from a number of studies suggests a limited level of communication about epilepsy within families living with the condition. There were many influential factors affecting the level of communication about epilepsy that families engaged in, namely; seizure control, time since diagnosis, family roles, family structure, and parenting style. Similarly, a number of challenges faced by families when choosing to communicate, or not, about epilepsy, were identified. These challenges largely centred around; limited epilepsy-related knowledge, parent worry, and parents' perceptions of themselves as role models for CWE. Methodological heterogeneity and variability in the strength of study design and reporting made the available evidence difficult to assess; hence, communication strategies employed by families living with epilepsy, the perceived barriers and challenges, and the impact of communicating remains unknown.

The scope of studies identified in this review highlights a distinct gap in the literature for studies focusing solely on family communication, specifically parent-child dialogue, about childhood epilepsy. While this review did report limited levels of communication about epilepsy in the home, little information has been ascertained relating to families who communicate openly about epilepsy. While it could be anecdotally assumed that openness might result in positive outcomes, limited empirical evidence exists to support such propositions. Further research is required in this area to establish why some families choose to talk openly about epilepsy and others choose to actively conceal the condition (Moffat et al., 2009).

Many of the challenges portrayed in this review can be categorised around broader issues such as parent's level of knowledge about their child's epilepsy and negative parental perceptions of epilepsy. These issues are closely linked to the finding that one in five parents of CWE did not sufficiently inform their child about his/her condition (Hirfanoglu et al., 2009). Feelings of being under informed about epilepsy can have important implications for both the CWE and his/her parent(s). A lack of epilepsy-related knowledge can leave children feeling unsupported by their family and unable to answer questions relating to their epilepsy. It has also been demonstrated that parents with less knowledge surrounding their child's epilepsy tend to impose more activity restrictions on the child. Austin et al.'s (2002) family-based psycho-educational intervention

yielded positive outcomes for overall family functioning, indicating that actively informing CWE and their parents about the condition may create a platform for family communication about epilepsy that is free from the barriers and challenges aforementioned. Future research should focus upon not only the strategies employed by families when conversing about epilepsy, but also the impact of a greater level of epilepsy-related knowledge on family communication, in order to inform the design of effective family-based communication interventions.

Considering the challenge of parents' negative perceptions of epilepsy, research suggests that epilepsy-related stigma can play a key role in the adoption of closed communication strategies in families living with epilepsy (Schneider & Conrad, 1980). Despite the current review of the literature revealing that parents consider themselves key role models whom children take their cues from relating to epilepsy and epilepsy-related stigma, many parents still opt to restrict communication about epilepsy both to individuals outside the home and within the family context. Fear of the negative social connotations that may be attributed to epilepsy in the public domain can cause parents to adopt closed communication behaviours when communicating with their child. Parents may also engage in limited epilepsy-related discussions with their child in an effort to avoid the risk of enacted stigma (Tröster, 1997). Reports of parental avoidance of the word "epilepsy" when communicating with their child could be an exemplary behaviour of 'stigma-coaching', whereby a parent may coach their child through their perceptions, attitudes, and behaviours (Thomas & Nair, 2011). Closed behaviours, such as not using the word "epilepsy", can actively relay to children that their epilepsy is something to be ashamed of and something that they should not talk about. This further perpetuates the stigma surrounding the condition (Schneider & Conrad, 1980; Scambler & Hopkins, 1986). Given the limited and heterogeneous nature of the evidence identified in this review, future research is required to more closely assess the relationship between family communication and epilepsy-related stigma.

Heightened parental supervision and activity restrictions were highlighted in this review as a challenge for CWE. Children reported being bothered by parents' felt need for supervision. Activity restrictions and parental hyper-vigilance can reinforce to children the restrictions that their epilepsy imposes on them and increase feelings of differentness (Jacoby & Austin, 2007), especially in comparison to siblings. These feelings may be further exacerbated by a tendency for mothers to make hostile comments towards CWE more frequently than their siblings. Future research investigating the relationships between family communications and parenting styles is required to understand why some parents impose greater restrictions on their CWE than others.

2.5.1 Strengths and Limitations of the Review

To the author's knowledge this is the first review to systematically examine evidence pertaining to family communication in the context of childhood epilepsy. A key strength was following recommended practice for conduct and reporting of systematic reviews in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). Although searches were undertaken across multiple databases and a deliberately inclusive search strategy was incorporated, the possibility cannot be entirely excluded that relevant papers might have been missed.

Within this review 14 studies focusing solely on family communication about epilepsy. In 12 of the included studies, data relevant to family communication about epilepsy were extracted either as a major, subsidiary and/or incidental finding. This may have an implication for the weight that can be attributed to some of the findings that were revealed as a small subcomponent of larger themes. However, given that evidence of this nature has not been previously encapsulated in one review, all relevant findings were included regardless of their scope. The review findings must also be interpreted bearing in mind the dated nature of a number of included studies; 1970's (n = 3); 1980's (n = 6); 1990's (n = 6); 2000's (n = 9); 2010's (n = 2). Given the time-span of the included studies (1977 – 2010), it is possible that macro-level changes in social processes such as parent-child communication have occurred over time. Indeed, the demonstrated impact of epilepsy-related stigma on parent-child discussions about the condition may have changed over time in light of the introduction of campaigns to combat epilepsy-related stigma within recent decades (Reynolds, 2000; International Bureau for Epilepsy, 2015). Despite this, all findings were included regardless of publication year in an attempt to unearth as much evidence as possible surrounding family communication about childhood epilepsy. It is also important to bear in mind when interpreting the findings the limited reporting (e.g., of response rates, seizure type, socioeconomic class and parent level of education) within the majority of the studies included in this review. Future research in this area should endeavour to represent these demographic and clinical details in order to gain a more in-depth insight into the interfamilial processes of families living with childhood epilepsy.

2.6 Systematic Review Conclusion

Family communication about epilepsy can impact in varying degrees on both family functioning and child and parent psychosocial wellbeing. This review of the literature brings to light a

number of factors from a child and parent perspective that may be associated with family communication about epilepsy. In-depth research examining the barriers and facilitators to family communication and their relationship with other variables, such as seizure control, epilepsy-related knowledge, perceived stigma and parenting style, is necessary prior to embarking on the design of an effective family-based communication intervention. In the proceeding chapters the methodology utilised in the present mixed-method investigation into the aforementioned under-researched area will be explicated.

Chapter 3: Methodology

3.0 Introduction

This chapter presents the methodology underpinning this two-phased mixed-methods inquiry. Initially, the study aims and objectives are outlined. This is followed by an overview of mixed-methods research, the philosophical paradigm of pragmatism that underpins mixed-methods research, and the advantages and disadvantages of implementing a mixed-methods design. Finally, the sequential exploratory mixed-methods design adopted in this study is explicated, including the specific rationale for implementing this design within the present study.

3.1 Study Aims

The aims of this two-phase mixed-methods inquiry are two-fold;

- To explore parent-child dialogue practices about epilepsy from both a parent and CWE perspective.
- To establish the relationship between parent-CWE epilepsy-related dialogue and a number of demographic, clinical, and psychosocial variables

3.2 Study Objectives

The objectives of *phase one* are to:

- Determine how, what, and when parents and CWE dialogue about epilepsy.
- Ascertain the context surrounding what informs parents and CWE's decisions to engage in dialogue, or not, about epilepsy.
- Identify barriers and enablers that might impede and/or encourage parent-CWE engagement in dialogue about epilepsy.
- Examine the positive and negative consequences for CWE and their parents of engaging in dialogue, or not, about epilepsy.
- Identify constructs related to epilepsy-related parent-child dialogue that warrant further quantitative investigation in phase two.

The objectives of *phase two* are to:

- Investigate the relationship between parent-CWE communication strategies and demographic variables, including; parent/CWE age, parent/CWE gender, and parent education level.
- Assess the relationship between parent-CWE communication strategies and clinical variables, including CWE's; seizure type, seizure severity, seizure visibility, seizure frequency, and family history of epilepsy.
- Assess the relationship between parent-CWE communication strategies and psychosocial variables for CWE, including; perceived stigma, illness attitudes, health-related quality of life, perceived social support, self-perception, need for epilepsy-related information and support, and perceived satisfaction with the level of epilepsy-related information they have received.
- Assess the relationship between parent-CWE communication strategies and psychosocial variables for parents, including; perceived stigma, response to CWE's illness, perceived social support, perceived impact of epilepsy on CWE and the family, need for epilepsy-related information and support, and perceived satisfaction with the level of epilepsy-related information they have received.

The hypotheses pertaining to these phase two objectives will be presented at a later point in section 7.2 of Chapter 7.

3.3 Mixed Methods Research

Over the past thirty years, mixed-methods research has emerged as an alternative to the dichotomy of qualitative and quantitative practices (Tashakkori & Creswell, 2007; Teddlie & Tashakkori, 2009). Philosophically regarded as the third wave, or methodological movement, mixed-methods research is deemed capable of bridging the 'either/or' qualitative/quantitative debate by recognising the importance and advantage of combining both methodologies (Olsen, 2004).

Mixed-methods research essentially attempts to gain from the wisdom of both qualitative and quantitative viewpoints (Johnson, Onwuegbuzie, & Turner, 2007). Most mixed-methods researchers agree that enhanced understanding of the research problem can be produced by

building upon the strengths and minimising the weaknesses of both qualitative and quantitative approaches in a single study (Doyle, Brady, & Byrne, 2009). Creswell and Tashakkori (2007) define mixed-methods as research in which data collection and analysis occurs, findings are integrated, and inferences are drawn using both qualitative and quantitative methods in a single programme of inquiry. This is the definition of the mixed-methods research design that I have chosen to adopt in the context of the present study.

Qualitative research is interested in understanding how people make sense of the world and their experiences (Merriam, 2009). Qualitative researchers place the person at the forefront of their methodologies, study things in their natural settings, and attempt to make sense of, or to interpret, phenomena in terms of the meanings people attribute to them (Denzin and Lincoln, 2005). This naturalistic approach to data collection and interpretation involves data being represented in a number of open-ended forms, such as interviews, drawings, conversations, photographs, all comprising a non-exhaustive list of interpretive materials (Willis, 2008). Informed largely by constructivist epistemology, qualitative research has come to the fore again in the past two decades (Morgan, 2007), a movement that Willis (2008) refers to as the postmodern movement. It is not the intention of qualitative exploratory research to generalize to the larger population but rather to develop an in-depth understanding of a concept or experience that represents the phenomenon under investigation, and to consider the transferability of the findings to other settings by providing a description of demographic and geographic boundaries of the study for the reader.

By contrast, quantitative research exists on the opposite side of the social research methodology spectrum. This form of research, although also interested in how people make sense of the world, focuses on a more objective interpretation (Bryman, 2012). Quantitative researchers seek close-ended information, such as those found in validated behavioural or performance scales and instruments (Creswell & Plano Clark, 2007). In the late twentieth century a shift was seen across the social research realm toward quantitative research as it was seen as a more generalizable form of data collection that was less influenced by personal interpretations and bias (Creswell & Plano Clark, 2007; Tashakkori and Teddlie, 2010). Despite the unbiased and broadly generalizable data basis brought to the fore by quantitative research, critics argue that this form of research alone does not bring to light the context in which people provide information on a certain research topic, and leaves the researcher with sparse and "skinny" data (Smith, 1983). Qualitative insights, when combined with quantitative data, as in the case of the present study,

can provide a well-rounded insight into the topic under investigation and allow for a more robust analysis (Tashakkori and Teddlie, 2010; Ivankova, Creswell, & Stick, 2006).

3.3.1 Pragmatism

The mixed-methods research approach employed in the present study is underpinned by the philosophical perspective of pragmatism. Informed by a pragmatic epistemology, mixed-methods research uses a dynamic approach to address complex multi-faceted research problems by combining qualitative and quantitative research methodologies into an independent study design (Johnson & Onwuegbuzie, 2004). Pragmatism acknowledges that alongside quantitative data, qualitative data may provide insight into the unknown and prove valuable in explaining and expanding quantitative results by enabling the researcher to understand the meaning of concepts from their individual perspective and experience (Creswell & Plano Clark, 2007; Cornish & Gillespie, 2009).

The choice of an appropriate paradigm or worldview is imperative as it provides additional justification for the use of mixed-methods research (Hall, 2013). Tashakkori and Teddlie (2010) suggest that a practical and applied research philosophy should guide the methodological choices made. As a research philosophy, pragmatism has gained considerable support as a foundation for mixed-methods research (Maxcy, 2003; Morgan, 2007; Feilzer, 2010). The pragmatic view largely focuses on the consequences of the research and "what works" in order to inform the problem under study (Cornish & Gillespie, 2009), attempting to fit together insights from qualitative and quantitative inquiries for a workable solution (Johnson & Onwuegbuzie, 2004). In this way a pragmatic approach, as seen in mixed-methods research, may provide the best opportunity for answering important research questions (Johnson & Onwuegbuzie, 2004).

Critics of mixed-methods research overwhelmingly point towards the incompatibility thesis as a basis for mono-method superiority (Brannen, 2005; Sale, Lohfeld, & Brazil, 2002). This philosophically grounded debate views qualitative and quantitative research as vastly different paradigms that are largely incommensurable (i.e. – incompatible for integration) (Bryman, 2012). This incommensurability stems from each paradigm's inherent epistemological and ontological assumptions, methods and values and that these are "inextricably intertwined" (Bryman, 2012; p. 453). However, proponents of the pragmatist viewpoint argue that no incompatibility between qualitative and quantitative methods exists; instead placing value in a

workable solution in order to achieve the greatest insights into research questions posed (Denzin, 2010).

A significant characteristic of the pragmatic approach is the importance placed upon the research question (Teddlie & Tashakkori, 2009). By adopting a mixed-methods approach, the researcher may draw from both qualitative and quantitative assumptions within the data in order to best understand the topic under investigation. In the context of the present study, the research questions are exploratory in nature; seeking to understand the under-researched area of parent-child communication surrounding childhood epilepsy. Given the dearth of empirical evidence uncovered via the systematic review of the research literature, a pragmatic approach has been undertaken to unearth the greatest level of novel information relating to this research area. A combination of qualitative and quantitative research methods are required to appropriately address the research aims highlighted at the outset of this study.

3.3.2 Advantages and Disadvantages of Mixed Methods Research

There are a number of advantages to implementing a mixed-methods research design. Applying both qualitative and quantitative methods to examine the research topic allows the researcher to provide a more complete, comprehensive and insightful view of the investigation findings (Greene, Benjamin, & Goodyear, 2001; Farquhar, Ewing, & Booth, 2011). For instance, although quantitative research alone may fail to gauge the context in which people behave, qualitative research can provide a more in-depth insight into the real-world implications of the research (Johnson et al., 2007). Furthermore, while the aim of qualitative investigation is not to generalize to the larger population (Field & Morse, 1985; Krefting, 1991), by combining qualitative and quantitative methods the generalisability of the findings is potentially enhanced (Johnson & Onwuegbuzie, 2004). Proponents of mixed-methods research suggest that the weaknesses inherent in the sole use of either qualitative or quantitative methods may be overcome by the combination of both approaches in a single study design (Creswell & Plano Clark, 2007; Doyle et al., 2009). Mixed-methods designs can also provide stronger evidence for a conclusion through convergence, divergence, and corroboration of findings (Johnson & Onwuegbuzie, 2004).

Despite these advantages of using mixed-methods research, some disadvantages of this approach are also apparent. Mixed-methods research can be a time-consuming and resource intensive process, particularly in the case of sequential designs whereby qualitative and quantitative methods are employed separately (Ivankova et al., 2006; Driscoll, Appiah-Yeboah, Salib, &

Rupert, 2007). Structured timelines and effective resource management can aid in overcoming this challenge. Additionally, while there is the challenge of uncovering conflicting findings within both methodological approaches (i.e. qualitative and quantitative), consistency can be restored through data integration (see section 3.4.1) and with the acknowledgement of the complexity of the phenomenon under investigation (Slonim-Nevo & Nevo, 2009).

3.4 Present Study Design

The present study employs a sequential exploratory mixed-methods design with two phases; a qualitative phase followed by a quantitative phase. In the initial qualitative phase semi-structured interviews will be conducted with CWE (6-16 years) and their parents (mothers and fathers) to explore parent-child dialogue practices about epilepsy; from both a parent and CWE perspective. In the quantitative phase, data will be gathered from specifically designed cross-sectional surveys. These data will be used to create a profile of CWE's (8-18 years) and parents'; perceptions of epilepsy, family communication patterns, demographic characteristics, clinical characteristics, and psychosocial wellbeing. The findings of each study phase will be presented and discussed separately, followed by a consideration of the integrated findings.

3.4.1 Rationale for Using a Sequential Exploratory Design

Drawing on the work of Doyle et al. (2009) and Creswell and Plano Clark (2007), a number of key factors were considered when deciding to implement a sequential exploratory design in the present investigation. These factors include the; various types of study design, timing of study phases, weighting of study phases, data integration approach, and advantages and disadvantages of a sequential exploratory design. The consideration of each of these factors is discussed below.

Type of Study Design

Creswell and Plano Clark (2007) posit that four primary mixed-methods study designs exist within the research literature, these are; triangulation, embedded, explanatory, and exploratory designs. Triangulation designs give equal weighting to qualitative and quantitative study phases, with each phase generally gathering supplementary data on the same topic. Conversely, embedded mixed-methods designs employ qualitative and quantitative study phases in order to address different aspects of the topic under investigation. Explanatory mixed-methods designs are sequential in nature (quantitative phase followed by qualitative phase), and typically favour quantitative methods. These designs are used when quantitative data alone is deemed insufficient to explain a research problem; the quantitative data is teamed with qualitative

findings in order to provide a greater understanding of the research topic. Finally, exploratory designs are also sequential in nature (qualitative phase followed by a quantitative phase), and are generally used in order for the initial qualitative findings to inform elements of the second quantitative phase, in the absence of other available evidence. An exploratory mixed-methods design is employed in the present study. Findings derived from the qualitative phase will serve to inform areas of particular interest relating to parent-child communication about epilepsy for examination in the quantitative phase.

Timing of Study Phases

The timing of study phases employed in the present study refers to the decision made regarding the temporal relationship between both phases (i.e. - when each phase was conducted). Two different design options exist within mixed-methods research with regard to timing; concurrent and sequential designs. Within concurrent designs, qualitative and quantitative study phases occur at exactly the same time. Within sequential designs, as in the present study, study phases occur chronologically (qualitative phase followed by a quantitative phase, or vice versa) in order for conclusions drawn from the first phase to lead to the formulation of components for the subsequent phase (Teddlie & Tashakkori, 2009).

The systematic review of the literature conducted at the outset of this study did not highlight an exhaustive list of areas relating to parent-child communication about epilepsy that warranted particular investigation. A sequential design was chosen within the present study, conducting the qualitative study phase prior to the quantitative study phase. In addition to the qualitative phase addressing specific research objectives relating to parent-child dialogue about epilepsy, the sequential design provided an opportunity for the qualitative investigation to identify areas of parent-child dialogue about epilepsy that may be further quantitatively examined. Additionally, the qualitative data may provide importance inferences relating to what psychometric measures to include within the subsequent quantitative study phase.

Weighting of Study Phases

The weighting of the study phases refers to the level of weight or priority afforded to each study phase within the overall mixed-methods study (Morgan, 1998). The qualitative and quantitative phases of the present mixed-methods study seek to answer different research questions. Within the qualitative phase, semi-structured interviews with CWE and parents will be conducted to elicit all available information relating to how CWE and parents dialogue about epilepsy

together, how this communication occurs and what facilitates or hinders this process. Subsequently, the quantitative phase will employ both newly developed and pre-validated measures seeking to assess how parent-child communication about epilepsy may be linked to CWE's and parents' psychosocial wellbeing. Therefore, given the diverse study objectives, and the ability for both phases to uncover different areas the interest, both study phases are given equal weighting in the present study.

Data Integration Approach

Integration is an intrinsic element of mixed-methods research (Creswell, 2013; Tashakkori & Teddlie, 2010; Moran-Ellis et al., 2006). Numerous guides and frameworks have been provided for the integration of findings uncovered via mixed-methods research (Tashakkori & Teddlie, 2010; O' Cathain, Murphy, & Nicholl, 2010). O' Cathain et al. (2010) identify three techniques for the integration of findings uncovered via mixed-methods research, these are; 1) triangulation protocol, 2) following a thread, and 3) the use of a mixed-methods matrix. Triangulation protocol was deemed the most appropriate form of integration for the present study as it allows for the interpretation of qualitative and quantitative findings following the separate analysis of both datasets.

The data elucidated from both phases of the present study will be analysed and discussed separately. Subsequently, the findings across both phases will be integratively discussed in order to provide a greater understanding of the topic under investigation; parent-child dialogue about epilepsy. The integrative discussion of the findings in the present study will be guided by the triangulation protocol framework described by Farmer, Robinson, Elliott, and Eyles (2006). This process of integration of the findings from the first and second phases of this study allows for several possible outcomes; convergence (where both sets of findings produce the same finding on a theme); complementarity (where both sets of findings feature a theme but have differing perspectives on that theme); silence (where one set of findings uncovers a theme whereas it appears silent in the other set); and discrepancy (where the sets of findings have conflicting findings on a theme). These outcomes will be discussed to allow for further support and elaboration of dominant themes observed throughout the mixed-methods findings.

Advantages and Disadvantages of a Sequential Exploratory Design

Creswell and Plano Clark (2007) identify a number of advantages inherent in implementing a sequential exploratory design, two of which are relevant to the present study. Firstly, the present

study design is straightforward to implement, allowing for a clear cut investigation into an under-researched topic. The qualitative and quantitative findings will allow for a rich and varied data source to analyse surrounding all aspects of parent-child dialogue about epilepsy. Secondly, a sequential exploratory design is particularly useful in the development of new psychometric instruments for measurement of relevant constructs in the second quantitative phase. This design will also aid in creating new conceptualisations surrounding parent-child communication about epilepsy in the absence of pre-existing theories.

As with all mixed-methods study designs, some disadvantages to employing a sequential exploratory design are also apparent. This design can be time-consuming to implement due to the conduct of two distinct phases. Sufficient time for data collection and analysis of two separate study phases followed by an integration of the findings must be taken into account when devising timelines. Additionally, issues surrounding ethical approval for two distinct study phases may contribute to the time-consuming nature of this study design (Creswell & Plano Clark, 2007). Due to the first phase of the present study informing elements of the second phase, ethical approval for each phase will have to be sought separately. These disadvantages can be overcome with the design of realistic and stringent timelines throughout the course of the research.

Summary

Following a consideration of a number of mixed-methods designs factors, including; the various design types, the sequence and weighting of the study phases, the data integration approach to be implemented, and the advantages and disadvantages of employing a sequential exploratory study design, a sequential exploratory design was chosen at the most suitable study design for the objectives posed by the present study. A visual representation of the overall study design is presented in Figure 3.1. The qualitative insights and quantitative data yielded in both phases of this study will provide a more in-depth and richer understanding of parent-child dialogue surrounding epilepsy, from both a CWE and parent perspective.

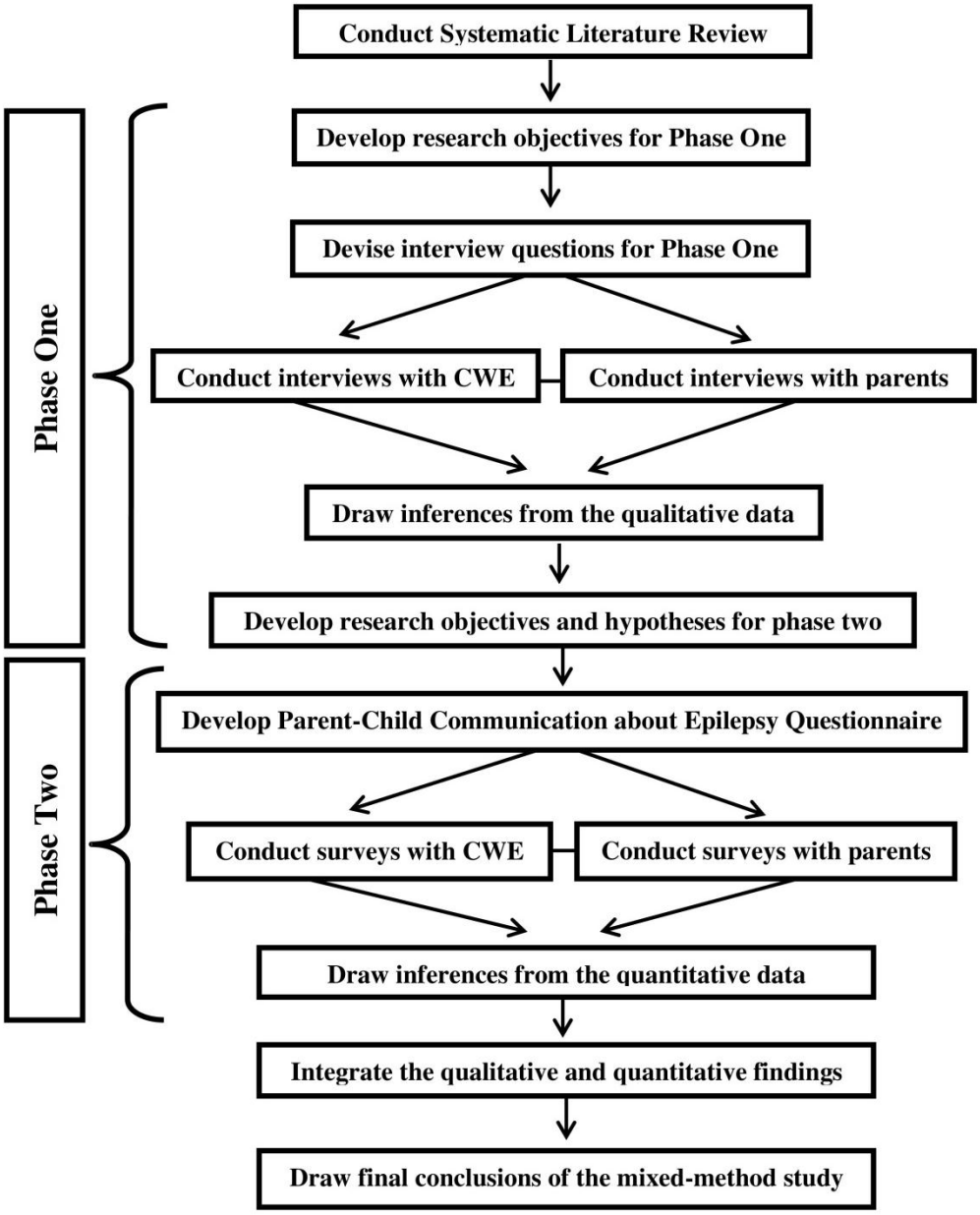


Figure 3.1: ***Visual Diagram of the Sequential Exploratory Design Process***

3.5 Conclusion

This chapter has provided an overview of the mixed-methods research design employed in the present study including the rationale for choosing a sequential exploratory mixed-methods design. The specific methods implemented in both phases of this study will be described in subsequent sections of this thesis, beginning with an explication of the qualitative method in the following chapter.

Chapter 4: Phase One: Qualitative Method

4.0 Introduction

In this chapter, the procedures involved in the first qualitative phase of this mixed-method inquiry are detailed. This chapter outlines the aims and objectives, processes involved in recruiting and selecting the sample, gaining ethical approval, data collection, and analysis procedures for phase one.

4.1 Qualitative Study Design

The first phase of this study employed an exploratory qualitative design.

4.1.1 Phase One Aims and Objectives

The aim of this phase was to explore parent-child dialogue about epilepsy within the family context.

The objectives of this phase were:

- To determine how, what and when parents and their CWE dialogue about epilepsy.
- To ascertain the context surrounding what informs parents and CWE's decisions to engage in dialogue, or not, about epilepsy.
- To identify barriers and enablers that might impede and/or encourage parent-CWE engagement in dialogue about epilepsy.
- To examine the positive and negative consequences for CWE and their parents of engaging in dialogue, or not, about epilepsy.
- To identify constructs related to epilepsy-related parent-child communication that require/warrant further quantitative investigation in phase two.

4.2 Phase One Sample

The eligible sample for this first phase included children living with epilepsy and their parents who met the pre-defined selection criteria.

4.2.1 Selection Criteria

The inclusion and exclusion criteria for CWE participants were as follows:

Inclusion criteria:

- CWE must have been aged between 6 and 16 years at the time of interview.
- CWE must have received a diagnosis of epilepsy and a prescription for anti-epileptic drugs (AEDs).
- CWE must have been diagnosed with epilepsy (idiopathic, cryptogenic, or symptomatic epileptic syndromes) for over 6 months.

Exclusion criteria:

- CWE presenting with an intellectual disability or developmental delay.
- CWE with any additional significant medical conditions (other than epilepsy).

The inclusion criteria for parent participants were that they were the parent/guardian of the CWE taking part in the study.

For CWE participants, the age range of 6-16 years was selected. As children move from middle to later childhood, issues of co-dependence and social activity come to the fore, especially in reaction to the possible over-protective strategy of the parent (Drotar, 1997). CWE across this wide age span were recruited during this first phase of the study to build a profile of parent-child interaction surrounding epilepsy. This inclusion criterion also responds to the literature in that persons with childhood onset epilepsy are at a high risk for poor psychosocial outcomes (Austin, Dunn, Johnson, & Perkins, 2004; Wallander & Varni, 1989). CWE were required to have a diagnosis of epilepsy over 6 months to allow for time for the family to establish a discussion, or not, around epilepsy in the home. This inclusion criterion also takes into account the time span at which children with chronic illnesses are generally told about their diagnosis by a parent or caregiver (Young et al., 2003).

Exclusion criteria were in place in an attempt to minimise any confounding variables that may adversely affect the findings of the study. CWE also presenting with intellectual disability, developmental delay, or an additional medical condition were excluded from this study because this group of CWE and parents might have different communication needs and additional concerns not directly related to epilepsy.

4.2.2 Ethical Considerations

Ethical approval for this study phase was granted from Dublin City University Research Ethics Committee (See Appendix B1) and the Temple Street Children's University Hospital Research Ethics Committee (See Appendix B2).

Informed consent was sought from all CWE and parent participants prior to the interview process. Informed consent was sought from parents for both; 1) themselves to participate, and 2) their CWE to be invited to participate (See Appendix C1). As all CWE were aged 16 years or under and could not provide legal consent, assent was sought from all CWE participants via age-appropriate assent forms (See Appendices C2 and C3). These assent/consent forms were provided to families within information packs for the study, accompanied by important study information for participants (See Appendices C4 – C6). Parents were encouraged to read through this information with their CWE to ensure that they fully understood the participation process.

Considering the issue of confidentiality, I was guided by the principle that the welfare of the child should be paramount (Department of Health and Children, 1999). In order to respect CWE's right to confidentiality, with their parents' permission, each CWE was invited to be interviewed on their own in a venue chosen by the CWE and family. However, if any CWE or parent expressed the wish for a parent to be present their wish was respected. Additionally, in order to respect the parents' rights to confidentiality, parent participants were given the opportunity to be interviewed alone or alongside their partner/spouse, again in a venue chosen by them. Finally, in order to protect all participants' confidentiality, all participants were first issued with an ID number by the researcher at the outset of the data collection process. Following this, CWE self-selected aliases were used to identify all participants (e.g. – "Taylor" and "Mother of Taylor").

Bearing in mind the sensitive topic to be discussed during the interviews, protocols were devised to outline the actions I would take if any CWE and/or parent (1) showed signs of upset/anxiety or became tired, (2) disclosed abusive behaviour, and/or (3) if a CWE had a seizure or became unwell (See Appendix D).

4.2.3 Recruitment

Participants for phase one were recruited via two routes; 1) via the neurology department of a major paediatric hospital, and 2) via an online and print advertisement facilitated by the national epilepsy association.

Route 1: Neurology Department of Temple Street Children's University Hospital (TSCUH)

Participants (CWE and their parents), who met the inclusion criteria outlined in section 4.2.1, were identified and informed about the study by a locally nominated gatekeeper at the CWE's hospital during epilepsy-clinic times. If families expressed an interest in participating in the study they were referred to me. I then provided the families with further information about the study and explained what their participation would entail. Study information packs (including a cover letter, parent information sheet, CWE information sheet, parent consent form, and CWE assent form) were distributed to interested families (See Appendices C1 – C6). Participants' right to decline to participate or withdraw at any time was explicitly outlined from the outset. Bearing in mind the varying levels of comprehension and reading ability of the CWE participants, two information sheets were devised; one for younger CWE (aged 6 - 10 years) and one for older CWE (or young people) (aged 11 - 16 years) (See Appendices C5 and C6). Following families' engagement with the information packs, if they still wished to participate in the study, interviews were arranged at a suitable time and location of their choice.

Route 2: Epilepsy Ireland (The Irish Epilepsy Association)

Within this recruitment path, CWE and their parents were accessed via advertisements displayed on the Epilepsy Ireland website and in the monthly Epilepsy Ireland members' newsletter (See Appendix C7). My contact details were included in this advertisement so that parents and CWE interested in participating could contact me directly. If families expressed an interest in participating I provided them with an information pack. Following their engagement with the information packs, if they still wished to participate in the study, interviews were arranged at a suitable time and location of their choice.

For both routes of recruitment, I telephoned the family forty-eight hours prior to the interview to ensure that the CWE and parents were still in agreement to participate and to serve as a reminder of the agreed interview arrangements.

4.3 Data Collection

This section outlines the data collection procedures for CWE and parent interviews.

4.3.1 CWE and Parent Interviews

Interviews were conducted with 29 CWE and 33 parents.

Pre-Interview Procedures

CWE and parent participants were assigned an ID number to anonymize data. Following this, CWE self-selected aliases and these were subsequently used to identify all participants (e.g. – "Taylor" and "Mother of Taylor").

Interview Guide

Two separate interview guides were developed; a CWE version (Appendix E1) and a parent version (See Appendix E2). The interview topic guides were developed to elicit information on demographic data (i.e. parent relationship to CWE and CWE characteristics including age, gender, age at diagnosis, seizure type/s, seizure frequency and medication/treatment regime), participants' insights into their experience of living with epilepsy, and issues related to the communication strategies employed when discussing epilepsy within the family. CWE demographic data was gathered solely during the parent interviews. All attempts were made to ensure that the interview guides for CWE and parent interviews were not inhibiting or rigid but rather allowed diverse and rich data to emerge to capture insights into parent-child dialogue about epilepsy.

Interview Procedures

Interviews were conducted with CWE and parents at a date, time, and location most convenient to them. In the majority of cases (n = 21) mothers were interviewed. Fathers were interviewed in two cases, and five families opted for both parents to be interviewed together. Of the 29 CWE interviewed, 26 participants were interviewed in their own home, two participants were interviewed in hotel lobbies, and one participant was interviewed in a room in the university. Of the 33 parents interviewed, 29 were interviewed in their own home, two were interviewed in hotel lobbies, and two were interviewed in a room in the university. CWE and parent interviews were conducted separately unless the CWE chose to have their parent present during the interview, and vice versa; his/her wishes were respected in this regard. Three CWE participants

were present for their parent's interview. Four CWE opted for their parent to be present during their interview. In all instances where parents were not present during the CWE's interview (n = 25) they were in an adjoining room to where the interview took place.

Interviews were digitally recorded. Parent interviews lasted between 13 minutes and one hour sixteen minutes, with an average interview time of 38 minutes. CWE interviews lasted between 3 minutes and 33 minutes, with an average interview time of 14 minutes. Despite the shorter duration, the quality of these interviews was not compromised; in a number of cases more closed-ended questions were utilised to place less weight on the child's verbal ability (Wilson & Powell, 2012) and create a more comfortable rapport with the researcher (Irwin & Johnson, 2005).

CWE participants were given the option of drawing pictures during the interview process as a stimulus for interactive dialogue and to assist with rapport establishment, enhancement of CWE's control, reduction of power differentials, and the creation an environment conducive to discussing sensitive issues (Angell, Alexander & Hunt, 2014). Eight CWE participants opted to create drawings, the majority of whom were in the younger age group category (6 – 10 years). Examples of these drawings are viewable in Appendix F.

It is also worth noting that all participating families received general feedback relating to this first phase of the study in the form of a concise summary of the key findings. This was posted to families approximately four months following their participation along with a letter of thanks for their involvement (See Appendix G).

4.4 Data Analysis

All interviews were transcribed verbatim. Data were analysed according to Braun and Clarke's (2006) thematic analysis framework. The six step process involved 1) becoming familiar with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and finally, 6) producing a report of the thematic findings. This form of analysis offered an inductive approach whereby themes are dependent on the emergent data itself rather than a priori theoretically-determined identification of what potential themes should constitute (Braun & Clarke, 2006).

To begin this thematic analysis, I listened to the audio files. I then read and re-read each interview transcript in order to make sense of the data. CWE and parent transcripts were

read and re-read separately, a process which enables the researcher to gain an initial idea of what was being said across each group (Liamputtong, 2009). Initial codes were then generated according to recurring topics and perspectives that emerged from the CWE and parent data. Initially data were manually coded, however, due to the large volume of emergent codes, all data was subsequently imported into the NVivo qualitative data analysis software package (QSR International Pty Ltd., 2012) to enable effective management of the data across the multiple datasets. Examples of the manual and NVivo coding processes can be seen in Appendices H1 and H2 respectively. Once all data was coded in NVivo, I began to search for recurring themes across these codes. A report of the thematic findings was produced encapsulating all emergent themes (See Appendix I). Once I had identified emergent themes and subthemes, these were reviewed by members of the research team where interpretations were validated through consensus and referral back to the original raw datasets. Each theme and subtheme was appropriately named and defined in accordance with the data it sought to capture. Relationships between themes were highlighted through constant comparison of themes within the data. Relevant field notes were also drawn upon throughout the analysis process.

4.5 Conclusion

This chapter described the qualitative method employed in the first phase of this mixed-methods study. The next chapter will present the qualitative findings for both CWE and parent participants.

Chapter 5: Phase One: Qualitative Findings

5.0 Introduction

This chapter initially details the profile of the sample for phase one, including demographic and clinical data. The qualitative findings for both CWE and their parents are then presented in terms of; parent-child communication strategies, the content and context of epilepsy-related parent-child communication, and the barriers, enablers, and consequences of communicating about epilepsy for CWE and their parents. For ease of navigation, CWE perspectives will be presented first followed by parent perspectives.

5.1 Sample Description (Demographic and Clinical Characteristics)

In total, 57 interviews were conducted within this qualitative phase. 28 interviews were conducted with parents and 29 interviews were conducted with CWE. In five instances, both parents opted to partake in the interview together; therefore, a total of 33 parents (26 mothers and 7 fathers) and 29 CWE (aged 6 – 16 years) participated in the study. The geographical distribution of participating families is illustrated in Fig. 5.1.

Figure 5.1: ***Geographical Distribution of Participating Families***

CWE participants experienced a range of seizure types, namely; simple partial, complex partial, generalized tonic-clonic, myoclonic, atonic, and absence. Mean age of diagnosis of the CWE was 7 years 4 months. The majority of CWE (n=25) experienced more than one seizure type. Seizure frequency varied considerably with 7 CWE having seizures daily, 4 having seizures weekly, 4 having seizures monthly, 8 having seizures several times a year, 5 having seizures

once a year, and 1 being seizure free at the time of the interview. Similarly, medication and treatment forms varied with 12 CWE receiving monotherapy, 16 receiving polytherapy, 1 receiving a combination of VNS treatment and monotherapy, and 1 not receiving any treatment at the time of interview. A full breakdown of CWE interviewee's demographic and clinical characteristics is outlined in Table 5.1.

Table 5.1: ***CWE Participant Demographic and Clinical Characteristics***

CWE Characteristics	
CWE Age	(Years)
Mean	11.67
SD	2.75
Range	6 – 16
CWE Gender	(N)
Female	19
Male	10
CWE Seizure Type	(N)
Simple Partial	7
Complex Partial	7
Generalized Tonic-Clonic	18
Myoclonic	5
Atonic	3
Absence	14
CWE Seizure Frequency	(N)
Daily	7
Weekly	4
Monthly	4
Several times a year	8
Once a year	5
Seizure free	1
CWE Time Since Last Seizure	(N)
During Interview	2
Hours	5
Days	4
Weeks	4
1 – 6 Months	8
7 – 12 Months	4
13 – 18 Months	1
Years	1
CWE Treatment Path	(N)
Monotherapy	12
Polytherapy	16
VNS (Vagus Nerve Stimulation) therapy	1
Not currently receiving treatment	1
CWE Age at Diagnosis	(Years)
Mean	7.33
SD	3.42
Range	2 – 14.5

A further detailed account of demographic and clinical characteristics for each CWE is provided in Appendix J, including; gender, age, school class, age at diagnosis, seizure type, time since last seizure, treatment path, family history of epilepsy, epilepsy terminology used within the family, and what parent was interviewed (mother, father, or both).

5.2 CWE Participant Findings

In this section, CWE perspectives on parent-child communication about epilepsy within their family will be presented. This will include an examination of the communication strategies CWE employ in relation to their epilepsy, the content of their parent-child discussions, the context of these discussions, and their perceived barriers, enablers, and consequences of parent-child communication about epilepsy. A full breakdown of the themes emergent from the CWE interview data can be viewed in Figure 5.2. Data in the form of italicized participant quotations will be integrated throughout the following sections in support of the emergent themes. To protect the privacy and confidentiality of participants, all names have been changed to pseudonyms selected by the CWE participants.

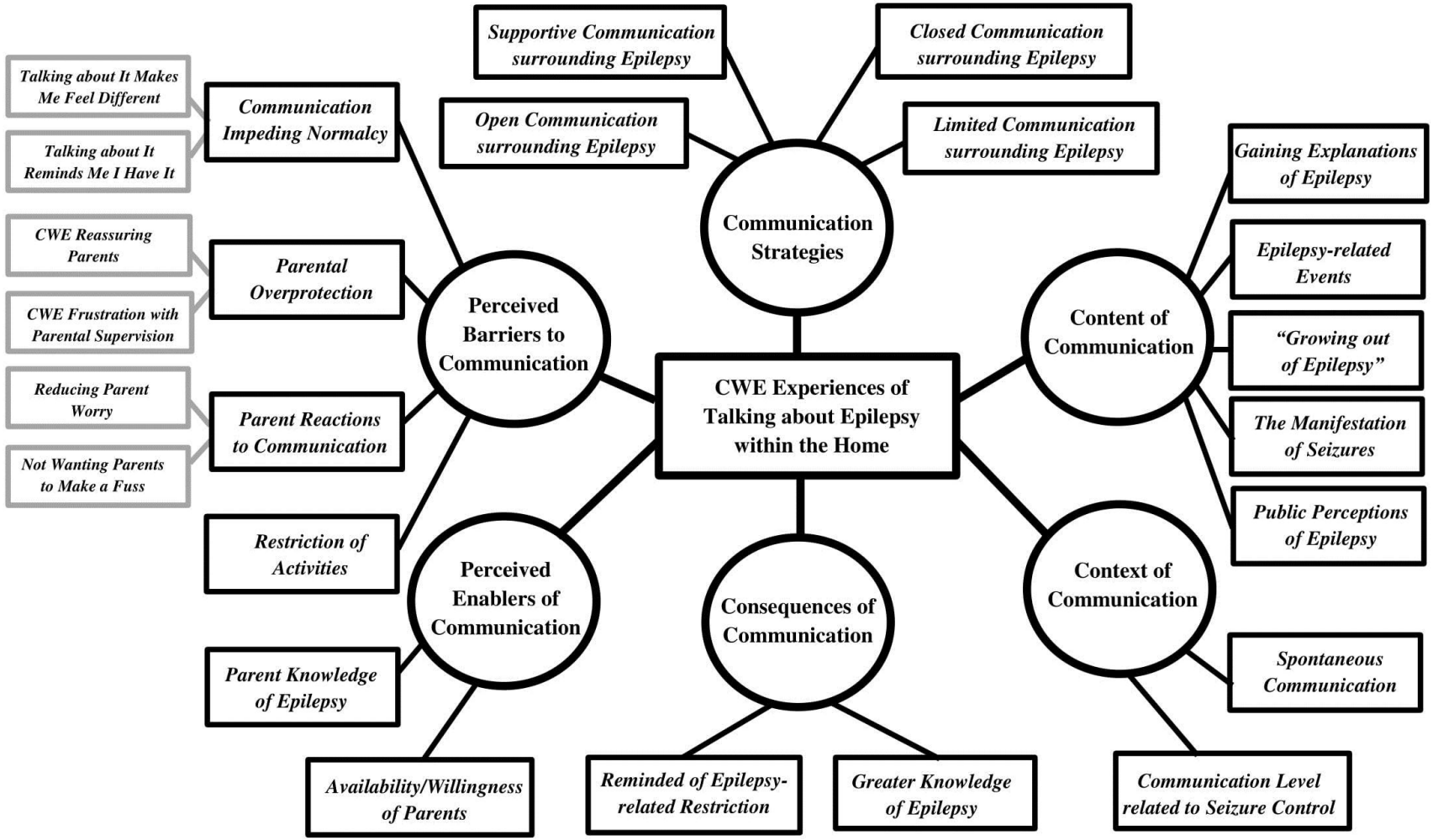


Figure 5.2: ***CWE Qualitative Findings - Thematic Analysis Network***

5.2.1 CWE Epilepsy-related Communication Strategies

CWE engaged in varied communication strategies when talking about epilepsy and epilepsy-related issues with their parents namely; open, supportive, closed, and limited communication pertaining to epilepsy (See Figure 5.2).

Open Communication Strategy surrounding Epilepsy

Many of the CWE interviewed reported adopting open strategies when communicating about epilepsy and epilepsy-related issues within the family. CWE spoke of how their epilepsy condition was freely spoken about by family members within the home. Additionally, CWE recounted how their parents in particular strove to maintain openness in relation to their epilepsy, ensuring that CWE felt comfortable with asking questions about their epilepsy and/or discussing it with them.

> *"I don't really have any problems talking to my Mum about it cause like she's always made it so clear that if I ever need to talk or even if I just want to like not talk she's there"* - Anna (aged 15 years)

A number of CWE who recounted adopting an open communication strategy around epilepsy stated how their parents conveyed to them that they were always available to discuss any epilepsy-related concerns they may have. CWE spoke of the importance and benefits of this open approach to communication as it allowed them to effectively cope with their condition in difficult times and made them feel reassured in the knowledge that they could talk about any epilepsy-related concerns freely with their parents if they arose. Some CWE cited how they felt this openness was a result of having a good relationship with their parent(s),

> *"Me and my Mum have a good relationship with just telling each other if I'm ever, so there's nothing I hide, just tell Mum everything"* - Michael (aged 15 years)

Supportive Communication Strategy surrounding Epilepsy

Another communication strategy CWE referred to was supportive communication. Supportive communication was largely child-led and held a particular goal of seeking psychosocial support from parents in relation to epilepsy, as opposed to the ad hoc general conversations seen within open communication. Within this strategy CWE felt supported by their parents when discussing their condition, with parents either effectively answering epilepsy-related questions or providing

emotional support to them in times of turmoil or uncertainty. CWE appreciated how this form of communication enabled them to cope better with the often unpredictable nature of their condition.

Fostering a supportive communication strategy within the home helped CWE to view epilepsy as a small part of their life that did not impose restrictions, to perceive their epilepsy in a positive light, and to reassure them they were not alone in navigating their condition – especially at time of diagnosis, as the following quotations illustrate.

> *"Yeah 'cause like my Mum, she would highlight all the good things and she kind of helped me realise that it wasn't everything and like she's the reason that I got better"* - Anna (aged 15 years)

> *"It made me feel a lot better, em, 'cause I didn't like being by myself with this because I, you know, I was kind of, I was very, very freaked out because I didn't know what was going on with me but once I told someone, you know, it was a lot better because… they were with you and they could sort it out with you so"*
> - Audrey (aged 15 years)

Closed Communication Strategy surrounding Epilepsy

A small number of CWE reported the use of closed communication strategies. These CWE relayed how they would not discuss epilepsy within the home and that, in some cases, parent-child dialogue about epilepsy was never engaged in.

> *"Literally every day I wouldn't just, I wouldn't just mention it ever"*
> - Ryan (aged 9 years)

This absence of communication about epilepsy resulted from a prevailing unwillingness of CWE to discuss the condition within the home.

> *"Well like no I'd never, I never really do much, like I wouldn't just come home or ever talk about it"* - Tom (aged 11 years)

Possible CWE perceived barriers to epilepsy-related communication, leading to the establishment of a closed communication strategy, will be outlined further in section 5.2.4.

Limited Communication Strategy surrounding Epilepsy

A number of CWE reported that the amount of epilepsy-related discussions they engaged in within the home depended on, and were limited to, particular situational contexts. CWE in these families relayed how they engaged in limited epilepsy-related discussions, often depending on the number of epilepsy-related events occurring at the time (e.g. – seizures, medical appointments, and/or changes in medication). Some CWE felt that it was largely unnecessary to talk about epilepsy with their family because there was no new information to be imparted or discussed. Also, and particularly in the case of milder seizure severity/greater seizure control, CWE felt that epilepsy did not impact on their life significantly enough to warrant frequent parent-child discussions and therefore the level of communication they engaged in was limited.

> *"We don't really talk about it that much 'cause it's not a big part of my life 'cause I've very mild epilepsy"* - Anna (aged 15 years)

CWE again echoed this limited approach by reporting that their condition was only really discussed at times when it was visible within the home (such as when taking medication or feeling unwell as a result of seizures).

> *"Whenever something comes up about it, like or if, now and again they'll ask me how I am with the medication or if I have a headache or anything like that but only if something comes up really"* - Audrey (aged 15 years)

5.2.2 Content of CWE Communication about Epilepsy

Six themes were identified in relation to what content CWE discussed when engaging in parent-child dialogue about epilepsy. These were; explanations of epilepsy, conversations about epilepsy-related events, conversations about seizure freedom and the possibility of graduating from their condition, conversations about how seizures manifest, and conversations about public perceptions of epilepsy (See Figure 5.2).

Gaining Explanations of Epilepsy

The ability to effectively learn about their condition was important to the majority of CWE interviewed. Many CWE relied on their parents to teach them about epilepsy and gain initial explanations of the condition. Due to the complex nature and unpredictability of epilepsy, CWE recalled instances in which parents sometimes struggled to explain many aspects of the

condition to them. According to CWE, explaining epilepsy and why epilepsy had occurred in their life was a major discussion point for families in the home.

> *"Only after the fit they'd be, I'd be saying like how did the… I don't understand how they cause it so I'd be asking how it causes, so I was like 'how did that one happen?' and each time they say 'I don't know'… I just ask them a question… they say 'I don't know', I don't really know, I can't remember"* - Ryan (aged 9 years)

CWE relayed that parents tailored their explanations of epilepsy to their age. Indeed, the epilepsy terminology used by CWE usually depended on factors such as age of CWE at the time of interview, and age of CWE's first seizure and experience with epilepsy. For instance, some CWE referred to absence seizures as "zoning out" or "dreaming", whereas many of the young people interviewed used full medical terminology for their seizures. Younger CWE (aged 6 - 10 years) relayed how parents tended to explain epilepsy in a way that they could understand without utilising epilepsy terminology jargon.

> *"They just said, I sort of forget what they said, but they said that sometimes my mind just goes and takes a break or something"* - Robyn (aged 10 years)

Such communication relating to explanations of the condition usually occurred around the time point of diagnosis, a time when parents were viewed as the primary information providers for CWE.

Conversations about Epilepsy-related Events

CWE spoke of how epilepsy-related conversations were often focused on epilepsy-related events, such as hospital and/or clinic appointments, medication routines, and seizures.

> *"Like eh if there was appointments like what day is it, what time is it like if it was in the morning like"* - Macklemore (aged 14 years)

Many CWE spoke of conversations surrounding medication routines and medication adherence. Such discussions seemed to have a positive impact on how CWE viewed their medication and why it was necessary. This encouraged CWE to adhere to their medication regime to maintain seizure control.

> *"Well I guess once I got a bit older like, my Dad obviously knows, well he's a doctor so he'd deal with a lot of patients and he'd deal with like teenagers who*

wouldn't be like taking their medication because they're trying to take control or they're trying to rebel or whatever, so like the three of us would have sat down and kind of had a discussion about how important my medication was and I was, I wouldn't, I would never stop taking it 'cause that's why I'm not having seizures all the time" - Anna (aged 15 years)

Medication-related discussions were particularly pertinent for CWE of an older age (i.e. – adolescents) who were more responsible for adhering to their medication routine. These conversations were particularly instrumental in ensuring CWE understood that a lack of consistency in taking medication could lead to deterioration in seizure control, which in turn could have greater consequences on their quality of life as they get older. Some CWE expressed the upset caused by medication-related conflicts. Rebecca, below, spoke of how disagreements relating to medication often caused her to not talk about her condition with her parents for fear of causing further clashes.

"Like at first like you could say at night now I could tell you now that I will be crying probably, em, well not like full on sobbing but like tiny tears, like I might cry about it and em sometimes my Mam and Dad don't know like how annoyed I get at it, like even sad like. I told like my friends but they're like wondering why my Mam and Dad don't know but I feel like this whole war about not taking my tablets or not taking them properly…" - Rebecca (aged 15 years)

CWE recounted how they felt their parents often overreacted when faced with issues of missing medication or taking medication at a time later than specified.

"Usually my mother at night time does always say 'Did you take your tablets?' and then in the morning time 'Have you taken your tablets and what time did you take them at?', 'cause she does go mad if I do get up too late and I do take them in the middle of the day or something" - Nikki (aged 15 years)

Conversations about Seizure Freedom and "Growing out of Epilepsy"

Some CWE found that the content of their epilepsy-related discussions with parents often centred on the seizure-free period and "growing out of epilepsy" (the possibility of CWE graduating from his/her epilepsy with age). These topics of conversation are specific to the unpredictable and often invisible nature of epilepsy.

Conversations surrounding these issues allowed CWE to understand changes in their medication levels and how these were related to their level of seizure freedom. Medication plans set in order to gain complete seizure control were often fully explained to CWE, giving them a sense of greater control over their condition.

> *"It's helpful because, you know, you can talk to them about meds, when they're going down, when they're going up, like when are they going down the medication so you can see, soon I'll be going lower on my medication, taking less tablets and soon I'll be off them"* - Tony (aged 13 years)

The majority of CWE interviewed who had between seven to twelve months of seizure freedom expressed hope when discussing the possibility of becoming seizure-free entirely.

> *"I mean I haven't had a seizure in nine months and if I don't have one in twelve months that practically either means that I don't have epilepsy anymore and I really can't wait 'til then"* - Jessie (aged 11 years)

Conversations about the Manifestation of Seizures

Many CWE were preoccupied with the physical manifestation of seizures and, specifically, what they looked like whilst having a seizure. Because many CWE had never seen a seizure and/or lost awareness during their own seizures, many did not know how a seizure may manifest. CWE relayed how their wish to learn about what their seizures looked like emanated from feeling scared during the seizure.

> *"I'd ask them what it looked like normally, because, em, I kind of want to know what I look like while I was having a seizure, 'cause, it'd be kind of scary"*
> - Hermione (aged 13 years)

The concept of seizures appearing scary to others was conveyed to a number of CWE, in some cases via discussions with their parents.

> *"Eh, I said like how do I take it and everything… and what's it like outside of it. She said it's scary"* - Rooney (aged 10 years)

For many CWE, parents remained the primary agent to tell them how they appeared during seizures, because they were most likely present during seizures in the past and could offer honest and frank answers to such epilepsy-related queries.

Conversations about Public Perceptions of Epilepsy

Some CWE relayed how the content of their discussions with parents sometimes focused on how epilepsy is perceived in the public domain. Parent-CWE conversations would range from focal points such as the occurrence of epilepsy-related news or articles in the media, to experiences of epilepsy-related stigma (such as teasing or bullying) and how to overcome the stigma that surrounds their condition.

> *"They would, like if they could they'd give me a solution to it, but they would help me like they always do, like if I was being bullied"* – Rebecca (aged 15 years)

CWE noted a distinct need for more public awareness relating to epilepsy, acknowledging the good that this would do for reinforcing positive images of epilepsy in the public domain as opposed to negative stereotyping. Many CWE agreed that greater awareness of the different forms of epilepsy and/or seizures would facilitate greater discussion about epilepsy and reduce the risk of discrimination.

> *"Yeah, not a lot is done for it like you'd never really hear of epilepsy at all, maybe if it was just taught more in school and just more even on the internet like cause a lot of people are on the internet these days, so if it was talked about more maybe on the internet… And positively instead of negatively"* - Aoife (aged 16 years)

5.2.3 Context of CWE Communication about Epilepsy

Two themes were derived pertaining to the context in which parent-child communication about epilepsy occurs, including; spontaneous communication and communication related to level of seizure control (See Figure 5.2).

Spontaneous Communication about Epilepsy

CWE relayed that communication about epilepsy with their parents would largely occur spontaneously and as a result of the topic coming up in conversation of its own accord. Epilepsy-related events behaved as a contextual catalyst for CWE to engage in epilepsy-related communication with their parents.

> *"Just at the time of it and stuff… I only really talk to her when I'm like about to go to an EEG or an interview up in (hospital)"* – Dave (aged 12 years)

Some CWE suggested that they would generally talk about epilepsy with their parents on thinking about epilepsy-related issues, however, as in the case below, this could often happen when CWE are alone, limiting the opportunity for parent-child engagement.

> *"So like we don't properly like sit down and talk about it or like it wouldn't be one of those like, if it like gets to me during the night like that's when I'd be like thinking about it, about everything and be like what the actual hell, why do I have epilepsy and it just won't go away"* - Rebecca (aged 15 years)

Communication about Epilepsy related to Level of Seizure Control

According to CWE, the frequency of parent-child conversations about epilepsy was strongly related to the number of seizures CWE were having at any given time. The majority of CWE reported less parent-child communication about epilepsy when experiencing a greater level of seizure control. The more seizures CWE were having, the more CWE and parents would talk about epilepsy. CWE did not feel the need to converse about epilepsy within the home when they were not having seizures frequently.

> *"Well the only person I really talk to in my Mum and… I don't talk that often to her about it because I don't have any seizures this year at all"* - Dave (aged 12 years)

Similarly, lower levels of epilepsy-related communication were relayed by CWE who were diagnosed with epilepsy at a young age, attributing this to gaining a greater level of seizure control over time. CWE appeared more likely to talk about epilepsy within the home whilst adjusting to living with epilepsy initially; a time when seizures were possibly more frequent.

> *"Like I've said it's nearly ten years that I've had epilepsy, there's nothing new to say at this point so like we don't really talk about it that much 'cause it's not a big part of my life"* - Anna (aged 15 years)

A greater level of seizure control led to CWE perceiving their condition as one which did not impact greatly on their life. This in turn lowered their felt need to talk about epilepsy with their parents. Indeed, several CWE with controlled seizures referred to forgetting they had the condition at all following the initial adjustment period.

> *"Yeah like sometimes like I actually forget I have epilepsy"* - Tom (aged 11 years)

"Well it's, like I've had it for like four years now so like it's like kind of forgotten about, or everyone's used to it" - Rebecca (aged 15 years)

5.2.4 CWE's Perceived Barriers to Parent-Child Communication

CWE expressed four main barriers when engaging in dialogue with their parents about epilepsy, including: communication impeding normalcy, parental overprotection, parental reactions to epilepsy-related communication, and restriction of activities as a consequence of epilepsy-related communication (See Figure 5.2 for these themes and their sub-themes).

Communication about Epilepsy Impedes Normalcy for CWE

For the majority of CWE, feelings of differentness were a major challenge when choosing to communicate, or not, with their parents about their epilepsy. CWE reported that talking about their epilepsy made them feel different from their peers and, at times, their siblings. This topic brought up issues of self-identity related to living with epilepsy, with CWE in the older age group reporting that they did not wish to be identified because of their epilepsy. Within this theme two subthemes emerged; talking about epilepsy encouraging feelings of differentness, and dialogue about epilepsy acting as a reminder of how epilepsy impacts on CWE's lives.

Talking about Epilepsy Makes Me Feel Different

CWE spoke about how communicating about epilepsy with their parents caused them to feel different. A number of CWE spoke about how such communication highlighted differences between them and their siblings in particular.

"Well it's not too hard because I take medicine… but it's a little bit hard because I don't, it's just, it's a little bit hard 'cause I feel different" - Robyn (aged 10 years)

CWE also noted how communicating about their epilepsy in general reminded others of their condition, something which they did not want to be defined by in the eyes of others.

"I guess I don't like talking about having seizures because that's not who I am, that's not what I am, that's not me. So I don't really like talking about that because and I don't like, like reminding people that I have epilepsy 'cause I do have it but I don't want them to constantly think of it when they see me, so like I don't want people to pity me because I have epilepsy or to feel sorry for me. So I guess it's just

like I don't really talk, like if I need to talk about it I can but I don't really talk about it that much" - Anna (aged 15 years)

Talking about Epilepsy Reminds Me that I Have It

A number of CWE felt that engaging in a discussion about epilepsy with their parents reminded them of their condition and the impact it had on their life and autonomy. This was especially relevant for CWE whose seizures were well controlled - in the absence of symptomatic reminders (i.e. seizures), epilepsy-related dialogue acted as a reminder of their condition.

"Talking about it to my family just well… It helps in some ways but it doesn't help in others 'cause it reminds me of the stuff when I'm just having fun and stuff and when someone rings you up and like ok and it's like awkward moment 'cause I'm like doing stuff and playing video-games and yeah, well we talk about doctor's stuff and… how good we're doing, how well, that's mainly it. . . It's not so helpful 'cause, I think I described it there, 'cause you're like focusing on other stuff and like… it reminds you that you have it and it reminds you of past experience of actual seizures" - Tony (aged 13 years)

Parental Overprotection in relation to Epilepsy

Many CWE spoke about parental over-protection and how their parents adopted a heightened level of supervision in order to reduce the safety-risks associated with seizures. The majority of CWE, particularly within the older age group, were cognisant of their parent's need to be vigilant; however, they found this a challenging aspect of talking about their condition. They reported a felt need to provide reassurance for parents in relation to seizures and became frustrated at continual parental supervision.

CWE Reassuring Parents

A large proportion of the epilepsy-related communication CWE engaged in involved them reassuring their parents in relation to their condition. CWE recounted how their parents would often seek their reassurance in relation to the stability of their condition, and that this dominated many of the conversations they had about epilepsy within the home. For CWE, reassuring their parents that everything was ok was viewed as a way of effectively reducing parent worry in relation to the condition, however, was also frustrating and tedious at times.

> *"I would mainly talk to my sister probably and maybe my Mam. If I was talking to my Mam I' just talk about not freaking out or, I don't know, that she doesn't' have to worry as much say, she would worry if I would stay up late but I know myself like if I stay up late I can get to sleep tomorrow, you don't need to panic about it"*
> - Aoife (aged 16 years)

> *"She was like just watch it, just take it easy like have an early night's sleep or whatever and then the minute my Dad heard he was in the room like are you ok, is everything ok, are you taking it easy, and I was like it's just a headache, calm down, it's nothing, don't freak out! That's the sort of thing that would happen if I mentioned anything"* - Aoife (aged 16 years)

CWE relayed how they would reassure their parents in relation to their condition in order to minimise the level of instruction they received, and in turn reduce the level of parental over-protection they experienced.

> *"It just kind of annoys me the way I had to do a big massive change about drinking water and like my Mam doesn't really get the fact that I'm better now so I don't have to drink as much so, but she just doesn't get it but, em, anyway she was making me drink water that day and I just, em, I wouldn't listen to her and I was like oh I'm not going to have a seizure, I know I'm not, and then my Mam was just like ok, ok I believe you"* - Jessie (aged 11 years)

CWE Frustration with Parental Supervision

Many of the older CWE (aged 11-16 years) expressed frustration at the perceived need for parental supervision. For this age group, autonomy, increased peer interaction, and independence were adversely affected by parents' heightened level of vigilance. Communication about supervision of CWE sometimes led to conflict between parents and CWE.

> *"Well, eh, not being able like, if I go babysitting I have to have like someone with me supervising me and the whole lot so it's kind of annoying having it and… My mother's always like 'supervise, supervise, supervise', like someone always has to be with me everywhere I go, so yeah, it's very frustrating"* - Nikki (aged 15 years)

> *"So if it just prevented me or even if it made her like if she rang up the girl's mother and was like just watch them, make them go asleep and it would ruin the whole sleep-over for everyone else like if I did that"* - Aoife (aged 16 years)

Parental Reactions to Epilepsy-related Communication

Parental reactions to epilepsy-related discussions were a barrier to CWE communicating about epilepsy with their parents. A large number of CWE mentioned how they had either not spoken about epilepsy-related issues, or not divulged full details pertaining to their epilepsy, with their parents in the past in order to not cause their parents worry. Similarly, many CWE spoke about how they did not want their parents to "make a big deal" out of epilepsy-related issues (i.e., not to dwell on their condition). Parents who CWE perceived as making a commotion in response to epilepsy-related issues were seen as annoying and a reason for CWE to engage in limited discussions about epilepsy with their parents.

Reducing Parent Worry

Some CWE were very aware of the potential worry that changes in their epilepsy condition could cause for their parents and/or siblings. These CWE felt that they could curb the level of parental concern through their epilepsy-related interactions with parents either by not talking or limiting discussions about epilepsy. A number of CWE alluded to limiting epilepsy-related communication in order to put their family at ease.

> *"Yeah, like I don't like to see them worried about me, like because it's something to do with the brain, anything to do with the brain people are always delicate about and like I wouldn't want to worry them as I said, and my sister I wouldn't want to worry her either"* - Aoife (aged 16 years)

Not Wanting Parents to Make a Fuss about Epilepsy

CWE spoke about how they found it challenging to talk to their parents about their epilepsy because of previous parental reactions they had experienced. Because of parental worry and over-protection, many CWE perceived their parents as consistently "making a big deal" about their condition when discussing it with them.

> *"Yeah and like I think I did have one [seizure] but I just never really mentioned it 'cause I didn't really know like and I didn't want to make a big fuss about it"*
> - Jessie (aged 11 years)

This was viewed as frustrating and a number of CWE relayed examples of times when they chose not to engage in a discussion about epilepsy with their parents because of the anticipated reaction of parents making a fuss. Indeed, some CWE recounted how they chose to speak about

their epilepsy primarily with the parent they perceived as more relaxed in response to epilepsy-related issues.

> *"A bit annoyed at her, yeah, just that made me feel like oh right, I can't really talk about medication with her, and she'll just freak out"* - Aoife (aged 16 years)

Restriction of Activities as a Consequence of Epilepsy-related Communication

A number of CWE relayed that the epilepsy-related dialogue they engaged in with their parents had a direct effect on their autonomy and ability to participate in peer activities. For example, some CWE felt they could not talk to their parents about their epilepsy, including non-disclosure of seizures, because doing so might result in parents restricting their participation in future leisure and social activities.

> *"Em, well there was a time in school when I had taken one the day before and I didn't want to say, and then I took one the next day in school but I didn't want to tell her because I didn't want her to think that I was only saying it to get out of school, but I had taken one and I didn't want to go home because I was after going home the day before"* - Rebecca (aged 15 years)

This theme was particularly pertinent for the older (11 – 16 years) age group. Many CWE within this subgroup found that activity restrictions caused additional problems not only for interactions within the home but also for peer interaction. As a result, this challenge acted as a major barrier for CWE when choosing to communicate with their parents about issues pertaining to their epilepsy.

> *"Well there'd be times when I want to go somewhere and if I take a fit I'd be iffy on telling my mother because it'd stop me from, it'll stop her from allowing me to go somewhere"* - Nikki (aged 15 years)

5.2.5 CWE's Perceived Enablers of Parent-Child Communication

CWE relayed two principal factors that acted as enablers to parent-child communication about epilepsy, including; parental knowledge about epilepsy, and the availability and willingness of parents to communicate about epilepsy (See Figure 5.2).

Parental Knowledge and Understanding of Epilepsy

CWE reported that they felt motivated to talk about their epilepsy at home when their parents were knowledgeable about epilepsy. High parental knowledge encouraged CWE to seek epilepsy-related information from their parents.

> *"Em, we just talked about, it was a couple of days after I got it and I just wanted to talk about it and I really, I didn't really understand it so I wanted my Mum and Dad to explain it"* - Robyn (aged 10 years)

Parents helped CWE to understand their condition and address any worries they might have.

> *"Yeah if I had worries it would be good to talk and like just find out things, my Mam's good for that, talking about stuff"* - Aoife (aged 16 years)

Parents were not only viewed by most CWE as knowledgeable but also understanding, reliable, and non-judgemental. This further encouraged CWE of all ages to confide in their parents about any epilepsy-related issues or concerns they harboured.

> *"Em, I don't really know because she understands me and that like if I went for a check-up she would still understand me and she will never not understand me"*
> - Cee Lo (aged 7 years)

There appeared to be an overall consensus among CWE that parents who possessed a higher level of knowledge about their epilepsy would encourage them to raise any epilepsy-related concerns with them.

Availability and Willingness of Parents to Communicate about Epilepsy

CWE relayed that the availability and willingness of parents to talk about epilepsy enabled them to engage in epilepsy related dialogue in the home. If parents were freely available to talk about epilepsy and epilepsy-related issues with CWE, CWE were more likely to facilitate such discussions.

> *"My Mum is always there like. My Mum, if I ever need her, she's always like just a shout away"* - Anna (aged 15 years)

Parental efforts to convey an availability to talk about epilepsy with CWE could therefore increase the level of epilepsy-related discussions within the home.

5.2.6 Consequences of Parent-Child Communication for CWE

The consequences of parent-child communication for CWE centred on two main issues, namely; communication acting as a reminder of epilepsy-related restrictions, and communication enhancing CWE's knowledge about epilepsy (See Figure 5.2).

Epilepsy-related Communication Served as a Reminder of Epilepsy-related Restrictions

A number of CWE felt that engaging in a discussion about epilepsy with their parents reminded them of their condition and the impact it had on their life and autonomy. This was especially relevant for CWE whose seizures were well controlled – in the absence of symptomatic reminders (i.e., seizures) epilepsy-related dialogue acted as a reminder of their condition.

> *"Maybe talking about the epilepsy because like I don't know like talking about it makes me not want to have it"* - Marie (aged 13 years)

A number of CWE actively weighed up the advantages and disadvantages that parent-child communication relating to epilepsy posed. Serving as a reminder of epilepsy-related restrictions and past memories of seizures were seen as the primary negative consequence of parent-child dialogue about the condition.

> *"Well, talking about it to my family just well it helps… It helps in some ways but it doesn't help in others 'cause it reminds me of the stuff when I'm just having fun and stuff and when someone rings you up and like ok and it's like awkward moment 'cause I'm like doing stuff and playing video-games and yeah, well we talk about doctor's stuff and like how we're doing, how good we're doing, how well, that's mainly it... It's not so helpful 'cause… 'cause you're like focusing on other stuff and like it doesn't remind you that you have it and it reminds you that you have it and it reminds you of past experience of actual seizures and it kind of, like it's only a tiny bit but it's like a little"* - Tony (aged 13 years)

Though this is largely a consequence relating to contextual factors surrounding communication about epilepsy, this highlights a possible negative impact of communication on CWE.

Greater CWE Knowledge about Epilepsy

Some CWE spoke of how they felt better informed about their epilepsy following engaging in a dialogue about the condition with their parents. Many of these CWE relayed an increased understanding of epilepsy following epilepsy-related communication with their parents. The ability to ask parents questions relating to their epilepsy enabled CWE to learn more about their specific diagnosis.

> *"Em, well like obviously the good thing is understanding stuff, em, bad thing… I don't think there really is a bad thing to be honest"* - Audrey (aged 15 years)

The greater level of knowledge facilitated by parent-child dialogue about epilepsy in turn had a positive effect on how CWE communicated about the condition with others, both within and external to the family environment.

> *"Em, I guess it's just, it's a lot better if you can talk about it. So like I know I might not talk about it a lot but I know I can so it's not something that I've had to keep secret or I've had to hide and it's made it a lot easier to deal with it because I can talk about it any time I like, so it's made it a lot easier"* - Anna (aged 15 years)

Additionally, emphasised feelings of not having to conceal their epilepsy helped CWE to view parent-child communication about epilepsy in a more beneficial light.

5.3 Parent Participant Findings

In this section parent perspectives on parent-child communication about epilepsy are presented, including; epilepsy-related communication strategies employed by parents within the home, the content of their parent-child conversations, the context of this communication, and their perceived barriers, enablers, and consequences of parent-child communication about epilepsy. A full breakdown of the themes emergent from the parent interview data can be viewed in Figure 5.3.

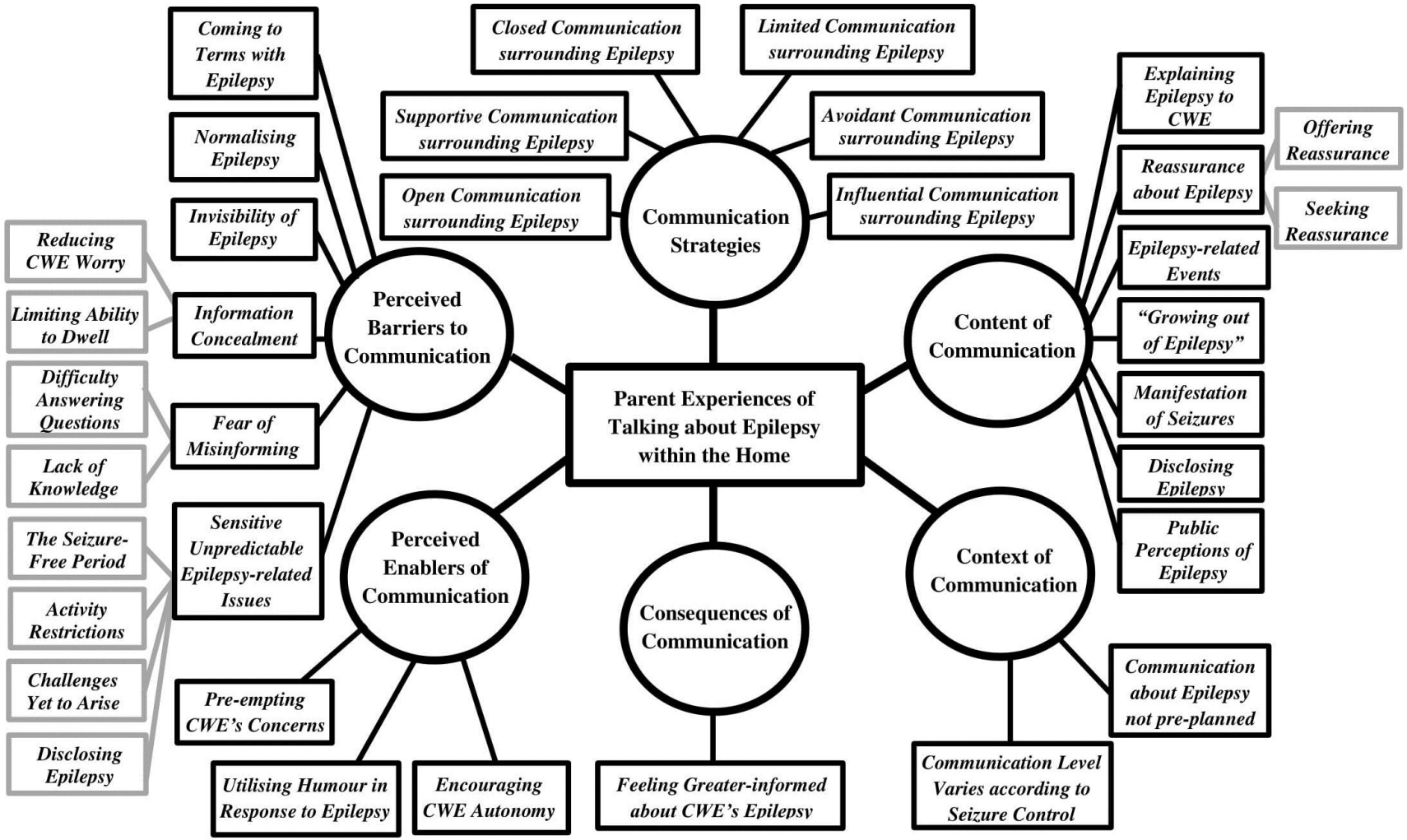


Figure 5.3: ***Parent Qualitative Findings - Thematic Analysis Network***

5.3.1 Parent Epilepsy-related Communication Strategies

Similar to CWE, parents engaged in varied communication strategies when talking about epilepsy and epilepsy-related issues with CWE. Six communication strategies were identified; open, supportive, closed, limited, avoidant, and influential communication about epilepsy (See Figure 5.3).

Open Communication Strategy surrounding Epilepsy

Parents spoke of the importance of open dialoguing about epilepsy within the family, citing benefits such as increasing CWE's knowledge about epilepsy and the opportunity for knowledge-sharing both within and external to the family context. A number of parents expressed initial difficulty in openly communicating about epilepsy with CWE and other family members. Due to the unpredictability of epilepsy and, often, the sudden onset of seizures, a number of families felt shock and bewilderment on receiving an epilepsy diagnosis for CWE. Such feelings posed communication challenges for families, with a number of parents relaying how they could not talk about the condition freely until a significant amount of time had elapsed. However, ultimately, an open communication strategy surrounding epilepsy was employed.

> *"I'd talk openly now, you know , it would have been a few years before we'd even really say what it was , he knew he was sick, cause he was always sick, he was always in hospital"* - Mother of Dave (aged 12 years)

For some parents, once the initial shock of diagnosis had elapsed, they made a conscious decision and effort to be open about epilepsy because they wanted to relay to CWE that epilepsy was not something to be ashamed of or concealed, thus reducing any negative impact that epilepsy may have on CWE.

> *"I mean I suppose the way I've always looked at it is I don't have the answers for her and I don't pretend to have them and I've been very open all the time so she'll chat away and we'll chat away and we'll kind of talk around it and I can't say definitely it's all going to be ok, it's not going to be ok, you know…. I don't mind talking to her about… Once the initial shock was over, my husband and I, particularly me, I decided we're going to be very open about this because it's not going to be some dirty little secret that she has where 'oh my God I've epilepsy,*

don't tell anyone', and then where she's walking around in terror of having a seizure/ We've been so open about it that it has kind of, I hope, minimalized it to a certain extent" - Mother of Anna (aged 15 years)

Parents were largely cognisant of how CWE perceived and understood their condition, and how ensuring openness about epilepsy within the home would ensure that CWE felt fully informed about epilepsy.

"I think it's just that thing of being really open with things, you know, and I mean like kids are incredibly flexible and they do, they kind of just get it… if someone actually takes time to explain to them 'this is what's going on'"
Mother of Cee Lo (aged 8 years)

Supportive Communication Strategy surrounding Epilepsy

A number of parents spoke of how they sought to create a supportive environment for CWE within the family home. Parents spoke of how they aimed to increase CWE's awareness of their condition in a bid to lessen any burden they felt due to their epilepsy. Parents in these families actively viewed themselves as a primary support giver for CWE when faced with epilepsy-related issues, often offering this support via conversations about epilepsy.

Unlike open communication strategies in which communication is general and free-flowing, supportive communication presents a deliberate creation of an environment in which CWE felt supported in living with their condition. Parents created this supportive communication environment by relaying to CWE the positive aspects of their epilepsy, explaining their condition in a child-friendly manner, and reinforcing to CWE that they could ask them questions at any time related to their epilepsy. Many of the parents who reported engaging in supportive communication often referred to communication about epilepsy as a key coping mechanism for both them and their CWE.

"We talked our way through everything and she'd have to be explained everything that's how we got through all… You have to talk to her, so talking is how she got through it" - Mother of Ruth (aged 13 years)

Parents perceived this supportive communication strategy as beneficial to CWE, with some parents finding that CWE were less anxious and/or worried about epilepsy after talking through epilepsy-related issues with them.

"Well we kind of just tell her anyway if she has any questions to ask us, now she might take a while to come around to you and say it but she will actually say it like. She is quite good now like, nothing kind of fazes her; if she wants to know the answer she'll ask you the question" - Mother of Selena (aged 11 years)

Such benefits of epilepsy-related communication for CWE reinforced to parents that talking about epilepsy was an effective way in which they could provide support for CWE when navigating their diagnosis.

Closed Communication Strategy surrounding Epilepsy

Some parents relayed the adoption of a closed communication strategy surrounding epilepsy within the family home. Closed communication, unlike open or supportive communication, did not allow for CWE or parents to discuss their thoughts or emotions surrounding epilepsy or epilepsy-related issues.

"To date we don't discuss it… her dad knows, you know. My sister knows, just in case I'm away and she has to babysit them but that's just it"
Mother of Taylor (aged 10 years)

In some cases, closed communication was maintained within families as a result of parents having little to no knowledge about CWE's epilepsy. This encouraged parents to adopt a closed communication strategy to avoid epilepsy-related questions from CWE which they might not be able to answer accurately.

"We don't really. If the kids ask a question or whatever, and the fact that I have such little knowledge of it, we try and answer as best we can but we don't"
- Mother of Colm (aged 12 years)

Further parent perceived barriers to epilepsy-related communication, which may result in the adoption of a closed communication strategy, will be discussed in section 5.3.4.

Limited Communication Strategy surrounding Epilepsy

Many parents, like CWE, relayed that the level of epilepsy-related communication they engaged in with CWE was limited, depending on contextual factors, such as CWE's level of seizure control and their own perceptions of epilepsy. A number of parents relayed how they did not have a problem communicating openly with their CWE about epilepsy; however, many felt that

it was unnecessary to talk about epilepsy and that their epilepsy-related communication was limited. Epilepsy and related issues often fell into the background of family life, only being spoken about when an epilepsy related event occurred (for example, the CWE's daily medication routine) or if "something came up".

> *"I mean we talk about it but we don't talk about it an awful lot, I think for Anna it's there, the taking of the medication is huge cause she has to take it twice a day and she's on a heavy dose, you know, she's on heavy doses. She hates that, that's a big issue but other than that I think she's almost kind of put it to the back of her mind"*
> Mother of Anna (aged 15 years)

> *"Audrey was diagnosed with mild temporal epilepsy, but luckily it is really mild and she is managing. It is not something I would go out of my way to talk about but if it comes up it is not a problem"* - Father of Audrey (aged 15 years)

Some parents' also spoke of how, although they felt comfortable informing CWE about their epilepsy, they often limited the level of epilepsy-related information that CWE received. Parents stated a number of reasons for this, including; CWE worry, the age-appropriateness of particular information, and issues yet to arise for the CWE/family.

> *"I have spared her a lot of the details 'cause she has enough to be going on but I'm always, I'm always investigating"* - Mother of Hermione (aged 13 years)

A number of parents' who adopted limited communication strategies believed that CWE had enough to deal with in their lives aside from epilepsy-related issues and were consequently selective regarding the finer details of CWE's epilepsy when discussing the condition with them. In some cases, CWE's age was an influential factor in parents choosing to engage in limited epilepsy-related communication.

> *"No 'cause she'll ask me and I'll sort of tell her. I mightn't tell her in any huge depth because she's thirteen and she has enough going on in her life, you know, she doesn't need to know the whole hundred per cent of anything"*
> - Mother of Hermione (aged 13 years)

Many parents adopted a policy of not communicating about future perceived challenges until this issue presented itself in the life of CWE. Parents in particular did not feel the need to raise future restrictions that epilepsy may impose on CWE until it was absolutely necessary to do so.

"You would shelter him about some things, the things he may not be able to do in the future. We will cross that bridge when we come to it"

- Father of Tadhg (aged 12 years)

Additionally, some parents felt that, as their CWE did not remember seizure events, they did not have to impart "too much" information about CWE's seizures to them in order to avoid causing fear or worry.

"We don't have a lot to add to it, as I said we don't want to give her too much information or wrong information so we have explained it that this is what it was, you weren't always aware of it happening" - Mother of Robyn (aged 10 years)

The desire to curtail the level of worry CWE had in relation to their condition motivated parents to adopt a limited communication strategy.

Avoidant Communication Strategy surrounding Epilepsy

Some parents engaged in communication avoidance strategies surrounding the topic of epilepsy. Unlike closed communication strategies, parents adopting an avoidant communication strategy did engage in some epilepsy-related dialogue with CWE where necessary; however, these parents largely avoided epilepsy-related discussions. Various reasons were expressed by parents for avoiding conversations about epilepsy with CWE. A number of parents adopted a *"less information is better"* approach when it came to CWE's own knowledge of their condition. Parents avoided talking about epilepsy with CWE not due to a lack of clinical manifestations of epilepsy but in order to minimise their level of anxiety/worry about epilepsy. Many parents felt that talking about epilepsy could relay to CWE that there was something wrong with them. This counteracted many parents' wishes to reinforce feelings of normality for CWE. For example, some parents opted to avoid discussing issues such as antiepileptic medication side effects with CWE.

"What I wouldn't talk about with Jessie is probably the side effects, things like that, 'cause knowing Jessie she'd have all of them… but yeah, I think the less she knows the better" - Mother of Jessie (aged 11 years)

Parents also spoke about avoiding interacting about epilepsy with their CWE because of their own feelings. One mother relayed how seeing her CWE having a seizure had caused her great

upset and rendered her unable to talk about epilepsy with her CWE for some time following the event.

> *"Like the day he took it I would be really upset, I wouldn't be able to speak to him that day, I would be really upset. Even though I know he is ok and that, I just get myself in an awful way; I just think horrible things that are going to happen to him"* - Mother of Rooney (aged 10 years)

Influential Communication Strategy surrounding Epilepsy

A final communication strategy parents reported engaging in was influential communication; whereby parents sought to influence CWE's attitude towards his/her epilepsy according to their own behaviours and beliefs. This process occurred in two ways; parents striving for CWE to view epilepsy in a positive light, and, conversely, parents relaying to CWE via epilepsy-related conversations that epilepsy was something that should be concealed.

The majority of parents were cognisant of the need for CWE to view epilepsy in a positive regard. Parents were aware of their influence when discussing epilepsy and often reinforced to CWE that epilepsy was not something that should hold them back in terms of future life goals.

> *"I'm always saying to Dave see you can go on to college and you can do everything. It's probably a harder road, you know, it's a tough road but em there's no reason why not"* - Mother of Dave (aged 12 years)

By consciously relaying positive messages to CWE in relation to their epilepsy, parents felt that they were able to positively influence CWE's confidence and self-esteem. Parents engaged in this form of influential communication in the hope of creating positive perceptions of epilepsy for CWE, enabling them to view their condition as one which did not limit their aspirations.

> *"Yeah and kind of positive, trying to look so that she wouldn't be too held back by it... I mean, you know, she's never going to be a pilot and, you know, horse-riding isn't going to be her thing but she had no interest in those anyway so I suppose it was to kind of push that she could do as much as she could and feel good about herself as well, you know"* - Mother of Anna (aged 15 years)

Contrarily, some parents, through epilepsy-related conversations with CWE, actively relayed to CWE the stigma that surrounds their condition. In cases where this did occur, this was often due to parents' previous negative experiences of epilepsy prior to CWE's diagnosis. Parents'

negative perceptions of epilepsy stemmed from factors such as experiences of encountering epilepsy (i.e. – witnessing seizures) prior to CWE's diagnosis or, as in the below case, as a result of a cultural stigma. By engaging in influential communication, these negative perceptions were actively relayed to CWE.

> *"I don't because it's like a stigma, you know where I come from, you know, like I told her too – sometimes when you want to marry to a family they actually do like a history and see if we have that kind of thing in the family and most times when you do, they won't, so…"* - Mother of Taylor (aged 10 years)

5.3.2 Content of Parent Communication about Epilepsy

Seven themes were identified in relation to what content parents discussed when engaging in parent-child dialogue about epilepsy within the home. These were; explanations of epilepsy, reassurance in relation to epilepsy, conversations about epilepsy-related events, conversations about seizure freedom and the possibility of graduating from their condition, conversations about how seizures manifest, conversations about the disclosure of epilepsy, and conversations about public perceptions of epilepsy (See Figure 5.3).

Providing CWE with Explanations of Epilepsy

Parents spoke about how they tailored their explanations of epilepsy to CWE's level of understanding, taking account of their developmental level in the terminology and analogies used; and also taking cognisance of their seizure type. For example, in the below account, Lucy's father is aware that she probably views epilepsy as the seizure type which most commonly manifests; drop attacks.

> *"And the way we have explained it to her… is if she is trying to do something on the computer or the television and it needs a certain amount of electricity and messages and stuff like that, or as I explained to her, my brain is telling me I need to pick up the cup… That is kind of what is happening with your leg. Sometimes it is just getting a little bit too much or a little bit too little and we need to get it right and the tablets are helping you to try and calm things down. She understands the falling, that is probably what she thinks epilepsy is"* - Father of Lucy (aged 7 years)

Parents of older CWE (aged 11 – 16 years) spoke of how they explained epilepsy to CWE in a more straight forward manner, relaying that often these young people would seek honest and

transparent explanations. Although such explanations were still provided in an age-appropriate manner to ensure understanding, more comprehensive explanations were given.

> *"No you have to say it out straight with her… like when we were in hospital like, that's how we got through it all was talking, you just have to have it in her language and try to make her understand that the doctors have seen one more wee thing on the cameras and their just taking, you know with MRI scans, taking photographs of your brain just to check it and talk her language… But she always understood"* - Mother of Ruth (aged 13 years)

Many parents referred to their explanations of epilepsy as a tool that helped CWE to cope with their condition. It was generally felt that CWE were able to come to terms with their diagnosis more effectively when all epilepsy-related information was appropriately explained and understood by them. Parents also spoke of how the question of "why me?" was posed a lot by CWE when engaging in parent-child dialogue about epilepsy. Parents were faced with explaining epilepsy to CWE whilst also helping them to cope with the condition.

> *"Well she talks to me freely about it, yeah, she asks me a lot of questions – 'why me?' you know, and all that"* - Mother of Taylor (aged 10 years)

A number of parents spoke of how they tackled such questions with comparisons to children also living with some form of illness more severe and debilitating than epilepsy.

> *"He has often said, 'why does this happen to me, why does this have to happen to me?' And I have explained to him, it is not really bad what he is doing, there are children out there a lot worse"* - Mother of Rooney (aged 10 years)

Parents felt that this would encourage CWE to not view their epilepsy in such a negative light, stating that they had to "get on with it".

> *"I remember him saying 'why do I have epilepsy?' and, you know, 'why is it just me?' like in the family and I mean I've said, you know, why does any poor child get cancer? You know, you've got epilepsy and it's not the end of the world, you know, there is much worse things you could have and… he's sort of saying well why are they all fine and I'm not… And I said… (siblings' names) have asthma, both chronic asthmatics and asthma attacks and all the rest of it so I said do you know what Dave you have epilepsy, get on with it"* - Mother of Dave (aged 12 years)

Reassurance in relation to Epilepsy

For a number of parents interviewed, reassurance in relation to epilepsy, both offered and gained, was the primary content of their epilepsy-related communication with CWE.

Parents Offering CWE Reassurance in relation to Epilepsy

Parents spoke about offering CWE reassurance about their epilepsy. Often this reassurance related to seizure control and the search for the optimum treatment path to reduce seizures and obtain seizure freedom.

> *"At the moment we are trying to reassure her that we are doing everything possible to get your leg working properly, to stop the falling, to make sure that you can do everything normal"* - Father of Lucy (aged 7 years)

Parents felt it important to reassure CWE in relation to activities missed due to epilepsy (e.g. – school trips) and assured them that what they were going through would not last forever, and that they were doing everything possible to improve their epilepsy (i.e. – lowering the amount of seizures).

> *"Yeah, you know, we talk about it more when she was tired going to school and she loves school, and she says 'Oh Mam I hate missing school', I said it's only 'cause of the epilepsy I said and we'll get the tablets straight, it won't be like this forever, you know"* - Mother of Hermione (aged 13 years)

Parents Seeking Reassurance from CWE in relation to Epilepsy

Often, parents acknowledged the irritability they may cause CWE in wanting to check up on them and ask about seizures, yet did this anyway for their own reassurance.

> *"Now that I recall it was one time we did talk cause I knew that it was worrying him but like he'd come out of hospital, he could be in there for two or three days or whatever and like we'd both try and talk to him about it and how is he feeling or what was he thinking or whatever … and I kind of think with him, he doesn't want to delve deep, you know, we've tried to be the psychologists but no, 'I'm grand Mum', 'Mum, I'm fine, leave me alone'"* - Mother of Dave (aged 12 years)

By engaging in this form of communication, parental anxiety related to epilepsy was lowered. Despite this, a number of parents acknowledged that the frequency with which they sought reassurance could be construed by CWE as an overreaction.

> *"Well we don't really talk about it to be quite honest but the thing is, I know there's a lot of children a lot worse off in the fact that they have worse epilepsy but we, I have to shout into his room… I always say if I had a euro for every time, you know, just to make sure he's ok because he spends a bit of time in there like and if I'm in the kitchen doing whatever and then I'm shouting in, if he doesn't answer back I have to run in thinking he's having a seizure or whatever, or like if I'm in the garden… It is, it can be, and maybe I'm kind of overreacting… I genuinely don't know but I do call into him an awful lot, you know, be watching TV and I'd just shout 'are you ok' and he'd shout back 'yeah', he probably gets fed up of me shouting in, don't you?"* - Father of Paul (aged 13 years)

Conversations about Epilepsy-related Events

Parents spoke of how the epilepsy-related dialogue they engaged in with CWE largely centred on epilepsy-related events, such as neurologist appointments or antiepileptic medication. The main reason for these conversations was to impart information about appointment plans, including what would happen at the appointment, in an attempt to alleviate any anxiety or worry CWE may experience.

> *"No we tell her like, like for instance if she has a MRI coming up about it that the doctor organized we tell her like. I wouldn't hide anything from her I'd tell her but I wouldn't… I'd tell her nearer the time so she can't kind of dwell on it, yeah"*
>
> - Mother of Selena (aged 11 years)

Parents and CWE primarily talked about three medication related issues; why medication is necessary (especially in cases of complete seizure control and/or seizure freedom), disagreements about medication adherence, and the impact of medication side effects. Parents reported explaining the necessity of CWE to take their medication in order to ensure complete adherence. This was particularly important for CWE who were responsible for taking their medication at their own discretion.

> *"Yeah she'd, basically the tablets, with her it's the tablets. But as I tried to explain to her, it's better to be taking the tablets than having seizures all the time and being wrecked. So she is getting very good now"* - Mother of Selena (aged 11 years)

Parents described how CWE often felt confused when faced with abrupt changes in dosage or antiepileptic medication type and this further called for the need to explain the importance of medication adherence to CWE.

> *"You know, but somehow she had the seizure by then again so we had to up it again, so that time she asked me as in – 'but I thought they were supposed to stop it' and I say like, you have to take it to make yourself feel ok. You know I just explain it to her as much as I can"* - Mother of Taylor (aged 10 years)

Some parents spoke of how CWE saw them as the person enforcing the medication routine, sometimes resulting in disagreements regarding medication and adherence to specific treatment plans.

> *"She kind of, initially we were on, I can't remember what the tablet was, and she didn't like it and we'd trouble like, she'd say to me 'I hate taking these tablets' but, you know, it's more that she would hate, you know, she'd say to her Daddy then she goes 'Mammy's after making me take this new one' and he's like 'It's not Mammy making you take this new one'!... I do the tablets you see and I do all the, just cause my husband works all the time, but she would see me then as the one making her take it when I'm not"* - Mother of Selena (aged 11 years)

A number of parents spoke of how, when engaging in a dialogue relating to medication side effects, they felt the need to rationalise the risk of taking medication despite the side effects listed. In particular, parents of CWE in the adolescent age group emphasised the importance of explaining medication side effects to CWE in order for them to be fully informed. Parents of CWE on a treatment path of polytherapy in particular found communicating about medication side effects with CWE to be troublesome. Some parents opted to discuss the possibility of medication side effects in full with CWE; this was especially relevant in the cases of older CWE (aged 11-16 years).

> *"I know so the side effects of the tablets they were mentioned a couple of days ago and she said I'm not going on that. I'm not doing that, no way. It's like your hair might fall out. Mention hair to a thirteen year old, forget it! Not good marketing,*

they won't do it! I sort of said you know anything at all, you know I was a teenager a long time ago. I said you can talk to me about it as well… We've been told it's like the side effects of the tablets and you know, we went through them, you know, once you get over sudden death or whatever you know you think oh Jesus, anything else is alright after that, you know, there's 500. I said you know Hermione if this happens to one person they could have an underlying condition, something else I said, they have to write it on the packet you know, I said it doesn't happen to everybody. But yeah the side effects, you know, sometimes maybe if it was left to the mother or the parents maybe to just go through them but I think everybody has to explain" - Mother of Hermione (aged 13 years)

Conversations about Seizure Freedom and "Growing out of" Epilepsy

Parents spoke of conversations they had with CWE relating to their period of seizure freedom (i.e., the length of time since CWE's last seizure).

"When he gets down about it, which wouldn't be that often, it is kind of a mixture between 'you are not that bad off, I know you have had a couple of seizures this week but it has been three weeks since you have had anything and we managed to X, Y and Z this summer and you didn't have a problem'. We kind of speak to him like that" – Father of Tadhg (aged 12 years)

Transparency when discussing this issue was imperative for parents. For example, explaining to CWE that the neurology team are unsure of the possibility of growing out of their condition was a way in which parents could effectively and honestly broach the topic with them.

"They can't tell us in neurology if it's for life or if it's only a phase, so I do say that to her, I do say look we don't know if this is for life or not, so you just have to deal with what you have" - Mother of Marie (aged 13 years)

A large proportion of the difficulties felt when discussing this sensitive issue stemmed from CWE's desire to graduate from their epilepsy. Parents did not wish to disappoint CWE or dash their hopes of this occurring by engaging in an open discussion with them about it. However, the majority of parents interviewed felt that clarity around the issue was essential.

Conversations about the Manifestation of Seizures

Conversations relating to how seizures manifest and appear to others prevailed in the majority of parents' experiences of talking about epilepsy with CWE. Answering CWE's queries about seizures which they could not themselves recall constituted a large proportion of the content which parents discussed with CWE. A number of parents were open and frank about the manifestation of CWE's seizures and the feelings of fear that seizures evoked for them.

> *"I have explained to him it's very scary to watch on my part, it's really scary to watch"* - Mother of Michael (aged 15 years)

Parents considered a number of ways in which to tell CWE about the appearance of their seizures. Some parents opted to use humour in their explanations.

> *"We sort of laugh at it at this stage because if you take it too seriously it will take over your life. And she would keep saying (brother's name) what do I look like and I'm thinking Jesus… She was killing herself laughing!... And they sort of made a dance out of it or something yeah but of course she never saw it herself. So she's saying what do I look like (brother's name) and I was thinking oh boys! You know they sort of talk about it in a, a sort of an amusing way"*
>
> - Mother of Hermione (aged 13 years)

Other parents had previously considered showing CWE a video of an individual having a seizure but relayed concern over frightening CWE unnecessarily. The level of explanation given relating to the appearance of seizures and the decision to show CWE such videos of seizures were largely dependent on CWE's age.

> *"I have toyed with the idea, I haven't done it yet, but I didn't know whether to show him somebody on the internet having one or not because he is always asking me what it is like. But I don't know if it would be too frightening for him to see it or not. He is still a bit naive and he is a bit young for his age even"*
>
> - Mother of Elvis (aged 7 years)

Parents overwhelmingly respected CWE's wishes when faced with the decision to view a seizure or not. They were also fully understanding of CWE's curiosity, however, encountered difficulties when faced with the responsibility of explaining the manifestation of seizures to CWE.

> *"He doesn't need to see that, he doesn't need to see himself going through that. [To child] I don't know if you've looked it up online or if you've seen any… and that's fine, that's fine. That's absolutely your choice darling of course but that would be the only thing. It's hard to talk to him about what he actually goes through because he doesn't know what he goes through"* - Mother of Michael (aged 15 years)

Conversations about Disclosing Epilepsy

Parents spoke of how CWE confided in them in relation to who they wished to tell, and not tell, about their epilepsy. In the majority of cases where such discussions did occur, CWE generally viewed disclosure of their condition as something that should occur on a need-to-know basis. Parent-child communication about disclosure often focused on parental disclosure to peers' parents, for example in the case of a sleepover or a peer activity in which the peers' parents would be primarily responsible for them. Parents often felt it important to explain to CWE why it was necessary to disclose their epilepsy in such cases.

> *"Em she doesn't like telling people that don't need to know. Yeah like I'd tell her if she was going to her friend's house and her friend's Mam didn't know I'd say well I have to tell the friend's Mam and she'd say but I'm not having seizures and I'd say I know you're not having seizures but we still have to tell the Mam just in case you do… so when I was telling (friend's name)'s Mam she was like does she really need to know I was like yeah cause she's in your care, you're in her care and she has to look after you if something happens"* - Mother of Selena (aged 11 years)

Parents were often tasked with reassuring CWE in relation to who was aware of their condition. Experiences of CWE querying who knew about their epilepsy were relayed by many parents.

> *"It's all a bit like, yeah she doesn't, she chats away to me about her wibbly legs and, that's what she calls them, we just call them the wibbly legs then and, em, yeah she'd chat away to me but nobody else like and mainly it's people in school, kind of, does that person know and you're like it's fine and just telling her that everybody has something"* - Mother of Kate (aged 8 years)

A number of conversations relating to disclosure touched upon reasons for CWE's wishes to not disclose their epilepsy. Parents relayed CWE's desire to not be different as a primary cause for non-disclosure, even in comparison to the disclosure of other conditions.

> *"No, I've asked him and he said he just doesn't want to be different. He doesn't mind having dyslexia and people knowing he's dyslexic but he doesn't want them to know he has epilepsy… I haven't pushed it, you know, I think he will confide in his friends when he feels ready to"* - Mother of Dave (aged 12 years)

Above all, when talking about disclosure issues, parents remained cognisant of CWE's wishes, acknowledging that their decision to disclose, or not, was paramount. However, when parents felt the need to disclose CWE's epilepsy to others (e.g. – another parent), this was largely discussed with CWE prior to its occurrence. In many instances, parent-child dialogue about disclosure centred on parents encouraging CWE to disclose their epilepsy to others, such as peers, classmates and sports team coaches/members. Parents relayed how they tried to frame the disclosure of epilepsy in a positive light, emphasising the potential benefits of disclosing, including educating others about the condition.

> *"Hermione has no qualms about telling anybody. I said you're to tell whoever, and I said explain to them, I said cause a lot of people have no idea, you know, explain it to them"* - Mother of Hermione (aged 13 years)

Parents also encouraged CWE to tell peers about their condition in order to lessen any personal burden they may feel by not disclosing their epilepsy to others.

> *"But em, so no he doesn't really like and I've actually asked him would he not confide in his friends and share it, do you know, not carry it on his own and they all bloody know anyway"* - Mother of Dave (aged 12 years)

By encouraging CWE to confide in others about epilepsy or epilepsy-related matters, parents felt that they could foster more positive perceptions of epilepsy and relay that epilepsy should not be a secret.

Conversations about Public Perceptions of Epilepsy and Epilepsy-related Stigma

Public perceptions of epilepsy and the stigma that encircles epilepsy in society was the content of epilepsy-related discussions with CWE for a number of parents. The issue of epilepsy gaining attention in the media acted as a positive catalyst for parent-child discussion according to many parents. Parents spoke of how CWE were able to accept their condition further on hearing of a famous celebrity who had epilepsy and/or a seizure. A rise in public awareness of epilepsy as a

result of a high-profile celebrity having the condition in turn had a positive impact on CWE's willingness to talk about epilepsy within the home.

> *"I told her about it, I told her you see it's… people do have it, you know … and she was like 'oh really?' you know, so… the way she reacted, I think she felt it was cool or something"* - Mother of Taylor (aged 10 years)

Although some parents reported never having experienced epilepsy-related stigma previously, a number of parents relayed how epilepsy had caused CWE to be discriminated against or treated differently in the past. Parents spoke of the challenges they faced when trying to communicate with CWE about how epilepsy may be perceived by the public. In the below example, Selena's mother is faced with explaining to her why a particular negative incident occurred due to her condition.

> *"We actually put her in a summer camp up… and when she went up, the leader of it said 'Selena, this is such and such, she has epilepsy too, you go together'… she came home and she was quite upset… Selena was like I didn't want anybody to know… So I went up to him and I said listen, Selena was quite upset yesterday the way you approached, announcing to the world that she had epilepsy, she had to be with her… I said just 'cause you've epilepsy doesn't mean they're gonna be friends… So eventually I'd say three days in people started treating her normal again and it kind of went back to normal and she was fine then but she just said to me… she didn't get it and then for me to explain it to her, it was just bizarre … We were just taken aback… He just assumed because they had epilepsy they should be together and then eventually we found out, he said, em, 'because if she has a seizure you can look after her cause you'd know what she'd be doing, you'd know what to do'… I was like you go back there and you show them, but it's just someone's logic, like does that make it ok? My husband said 'that's mad, that just proves to Selena that the way she does it is right', cause of what he did she keeps it to herself, if you need to know she'll tell you, if you don't she won't and his reaction, an adult, kind of confirmed to her well I am doing it the right way"*
>
> - Mother of Selena (aged 11 years)

Often, stigma experiences such as the example recounted above caused CWE to confide in their parents about why such events occurred. Parents spoke of instances in which they had to explain to CWE why a stigma existed in relation to epilepsy, whilst also relaying to CWE that epilepsy

is something that should be spoken about freely. Parents often felt it was their responsibility to eradicate any perceived stigma CWE may feel following such events by talking about epilepsy-related stigma and instances in which it may have impacted on them.

5.3.3 Context of Parent Communication about Epilepsy

Two themes were derived relating to the contexts in which parents communicated with CWE about epilepsy, these were; communication about epilepsy not being "pre-planned", and level of communication relating to level of seizure control (See Figure 5.3).

Communication about Epilepsy not "Pre-planned"

All of the parents interviewed that opted to communicate about epilepsy with CWE appeared to do so in a laid-back and informal manner. Many parents spoke of how normal parts of the day-to-day routine, such as walking the dog, or casually talking to family members in the kitchen would sometimes bring about the discussion of epilepsy-related topics.

> *"The thing I have found most helpful of all is to walk the dogs, and it's very easy to talk when you're walking the dogs , I mean it isn't that we sit down and have these deep conversations, we walk the dogs and the dogs and the dogs are running hither and tither and we're talking about the dogs and then it'll come up so I think that's what, you know, that's what's kind of the conduit then, you know, we'd chat about nothing in particular and we're not looking at each other and we're walking away and then she'll say something"* - Mother of Anna (aged 15 years)

In keeping with this laid-back approach to talking about epilepsy within the home, a number of parents conveyed how the family would not engage in communication about epilepsy as a group, but rather smaller one-on-one conversations were likely to occur relating to the condition.

> *"I suppose we don't actually sit down as a family and talk about it but I would talk to (father's name) or I would talk to (brother's name). It would be all talking individually; it wouldn't be a sit down conversation"*
>
> - Mother of Macklemore (aged 14 years)

Parents remained mindful of the need to maintain a laid-back approach in relation to talking about epilepsy at all times in order to encourage CWE to feel comfortable when engaging in a dialogue about epilepsy.

"Maybe on the visits to the doctor, even going up the stairs I try not to sit and look at him and talk about anything really. It just doesn't work, boys like talking ear to ear and driving in the car maybe I just throw in little nuggets. Climbing those stairs or when we go for our croissant beforehand or after our chicken wings or whatever I just say things like, 'you heard (doctor's name) say how important it is to take stuff.' Or I say to him, 'how do you feel Tom?' 'Good.' Boys, 100% a boy"

- Mother of Tom (aged 11 years)

Level of epilepsy-related communication varies according to seizure control

Parents alluded to how the family would almost "forget about" epilepsy when seizures did not manifest. Because epilepsy can become an invisible condition in the absence of seizures, this lack of visible reminders that comes with greater seizure control often caused families to overlook epilepsy in day-to-day life.

"Eh, there's times when she's really well when actually we just kind of forget about it, we forget it then" - Mother of Cee Lo (aged 8 years)

However, in times during which seizures were more present in the lives of CWE and their parents, parent-child discussions about epilepsy would mostly occur around the time of an epilepsy related event such as a seizure or a hospital appointment. Parents relayed how CWE were more likely to speak about epilepsy with them following a seizure. Similarly, parents themselves were more likely to seek epilepsy-related communication with CWE at this time.

"Yeah, yeah, definitely, I do be trying to talk to her more about it, especially after she'd had one, do you know" - Mother of Nikki (aged 15 years)

Parents spoke of how CWE particularly sought to talk about epilepsy following a seizure, as this is when they were most in need of emotional support.

"She very seldom talks about it only when she has one and then for a wee while after it she may be a wee bit just upset but after that she never talks about it"

- Mother of Ruth (aged 13 years)

5.3.4 Parents' Perceived Barriers to Parent-Child Communication

Six themes relating to barriers parents faced when communicating with CWE about epilepsy were identified, namely; coming to terms with the epilepsy diagnosis, normalising epilepsy, the invisibility of epilepsy, information concealment, fear of misinforming CWE, and discussing sensitive unpredictable epilepsy-related issues (See Figure 5.3 for these themes and their sub-themes).

Coming to Terms with Epilepsy

Communicating about epilepsy at the time point of diagnosis presented a particularly salient barrier for a number of parents. Parents spoke of their initial difficulty in overcoming shock in relation to CWE's diagnosis and how this impacted on their ability to talk about epilepsy within the home. Indeed several parents recounted how they could not find the words to talk about CWE's epilepsy at this time.

> *"All I could think of is what she wouldn't be able to do, so I mean, you know, she was six years old and I was thinking, oh my God, she'll never go to college, oh my God she'll never get married, you know, but it was like this catastrophe had happened and I couldn't speak the words. I mean I told nobody for about eight or ten months because I just couldn't talk about it, there were no words, I just couldn't talk about it at all, so we just, it was just the two of us, (father's name) and myself and he couldn't talk about it"* - Mother of Anna (aged 15 years)

The upset that parents felt at this time when attempting to settle into life with epilepsy often caused them to be unable to talk about epilepsy, both with CWE and in general. In some cases, parents likened the shock of CWE's epilepsy diagnosis to a death.

> *"We didn't, I actually couldn't even speak about it, I mean it was like a death actually, I was that upset about it"* - Mother of Dave (aged 12 years)

Normalising Epilepsy for CWE

Parents spoke of their perceived need to normalise CWE's epilepsy as a potential barrier to how they communicated with CWE. Parents believed that they played a key role in encouraging CWE to view their condition as a normal part of their everyday family life. For example, normalizing epilepsy involved parents ensuring that their communication with CWE did not

make them feel different from their siblings. A number of parents were especially cognisant of the language they used when relaying to CWE this sense of normality surrounding epilepsy.

> *"At the moment, we are trying to reassure her that we are doing everything possible to get your leg working properly, to stop the falling, to make sure that you can do everything normal. And just tell her that there are some things going on with you, you are falling and that, but you have so many talents that other children would love to have. You are so brilliant, you are so beautiful, or whatever, you are so special. But to make sure that you are not special because you have these illnesses, you are special, full-stop. There is a danger there as well because I don't want her thinking that, because she does get some special treatment, like any sick child, but that is not because of this. It is not as a result of it because there would be a danger of, if I want to get attention…. Children can be clever. She knows that she is normal but she has a few things going on, but we all have things going on"*
>
> - Father of Lucy (aged 7 years)

Many parents recounted how they reinforced to CWE that their epilepsy did not restrict them in any way or make them different in comparison to other children without epilepsy. Helping CWE to avoid feelings of differentness in response to their epilepsy was imperative for parents. The majority of parents interviewed felt that being treated differently as a result of epilepsy was a major concern for CWE.

> *"I'm always saying to Dave, see you can go on to college, and you can do everything. It's probably a harder road, you know, it's a tough road but em there's no reason why not"* - Mother of Dave (aged 12 years)

By entering into a dialog about how epilepsy does not restrict them, parents attempted to relay to CWE that they could achieve as much as children without epilepsy. Parents not only wished to reinforce the idea of "normality" in comparison to peers but also sought to help CWE to avoid feelings of differentness in everyday family life and sibling relationships.

> *"Yeah and that was a major problem for Ruth, and all she ever wanted to do was just to be treated like everyone else, so this was singling her out, and she was not a happy camper at all"* - Mother of Ruth (aged 13 years)

For example, the mother of Ruth (above) relayed concerns that epilepsy-related communication may leave Ruth feeling "singled out" in comparison to her siblings. This created a barrier for

parents when communicating about epilepsy as they often did not wish to treat CWE differently by engaging in dialog with them about their condition. Similarly, parents did not wish for their actions to infer differences between CWE and their siblings.

> *"I suppose it has impacted on the family because to a certain extent with it you're kind of always thinking ahead, and you're trying not to make her different … so in a way, it has made the other children different in that no more than sleepovers or things like that, you kind of adjust so that her experience of growing up won't be too different"* - Mother of Anna (aged 15 years)

The Invisibility of Epilepsy

Parents found the invisible nature of epilepsy to act as a barrier to discussing epilepsy with CWE; both when choosing to raise epilepsy-related issues within the home and when discussing instances of CWE choosing to conceal epilepsy outside of the home. The majority of parents relayed that, aside from medication routines, they did not discuss epilepsy within the family home when CWE were not having seizures. A greater level of seizure control afforded some parents the opportunity to not discuss epilepsy with CWE.

> *"We're so used to it now that it doesn't really affect us like…. Sometimes she might, sometimes she might not, but she wouldn't be telling me the ins and outs of why I have it, you know. She was getting there, and I got a booklet, but she hasn't asked for the booklet, it's still in the press. I don't want to give it to her until she asks for it, yeah"* - Mother of Selena (aged 11 years)

Many parents, of CWE who maintained a high level of seizure control at the time of the interview, alluded to how the family would generally forget about the condition in the absence of seizures.

> *"Eh, there's times when she's really well when actually we just kind of forget about it, we forget it then"* - Mother of Cee Lo (aged 8 years)

Parents highlighted that a lack of visible signs of epilepsy discouraged them from discussing epilepsy-related issues with CWE. This presented a barrier for parents in choosing a time to talk about epilepsy with CWE, with a number of parents stating that they would rather not bring up the topic of epilepsy if it was not a pressing matter at the time (i.e., without the occurrence of an epilepsy-related event).

Information Concealment

Parents revealed instances of limiting the amount of information relating to epilepsy that they made available to CWE. Many parents felt that some information, particularly relating to medication side effects and Sudden Unexpected Death in Epilepsy (SUDEP), was inappropriate for CWE's age (particularly in the 6 – 10 years age group) because it would unnecessarily increase CWE's level of epilepsy-related worry and cause them to dwell on their epilepsy condition. Parents felt that by lessening the level of information that CWE had access to in relation to their epilepsy, they could both reduce CWE's level of worry about the condition and limit their ability to dwell on their epilepsy.

Reducing CWE Worry

Parents encountered specific challenges when seeking to limit CWE concern about epilepsy through reducing the level of information relayed to them. At times, limiting the amount of information delivered to CWE proved challenging especially in instances such as doctor's appointments or when CWE asked specific anxiety-provoking questions about their epilepsy condition.

> *"Well, I didn't want him knowing about that ESES… that he got. So when (neurologist's name) was talking to me about that, I asked him to leave the room, and some things I would think it's better that he doesn't hear…I mean I don't like him hearing any of that, and he did take wind of the … get wind of the brain tumour business so I said no, that it wasn't, it was just being investigated and covered it that way. He's too much to worry about"* - Mother of Dave (aged 12 years)

Parents also spoke about limiting the frequency with which they communicated with CWE about epilepsy and epilepsy-related issues as a means of preventing CWE worry. Many parents opted not to stimulate a conversation on the topic of epilepsy often because they felt this would raise concern for CWE and make them perceive epilepsy as a matter of greater importance and/or worry.

> *"I wouldn't speak to her about the risk of anything happening to her, you know, if I wasn't here. The last incident where her head was actually hanging over the bed, her airway could easily become blocked. I would never speak to her about that,*

about the worries and concerns I would have about that happening if I was not here…. That is what I do worry about, and I would never discuss that with her"

- Mother of Macklemore (aged 15 years)

Limiting CWE's Ability to Dwell on Epilepsy

Parents often limited their epilepsy-related discussions with CWE because they did not want CWE to dwell on their epilepsy or on any restrictions that their condition may impose on them. Parents also did not want to increase the potential risk of framing epilepsy in a less favourable light.

"I wouldn't want to scare her about certain things; you know like 'don't do this in case you have a seizure', 'don't do that in case you have a seizure'. I wouldn't want to put that in her mind, you know, I don't want her to dwell on it"

- Mother of Taylor (aged 10 years)

Parents were conscious of the level at which CWE dwelled on their condition and remained cognisant of the impact that parent-child communication about epilepsy could potentially have.

"I'd be more firm with the epilepsy because, as I said, she's a child that would linger on it. If she didn't get her own way, she'd dwell in herself a lot, and I have to stop that …. But I'll talk to her about whatever, you know, anything but I don't want her to be fixating about it all the time, she has to get on and live her little life as well, you know, it shouldn't be a big shadow hanging over her"

- Mother of Marie (aged 13 years)

Parents were above all mindful of the barrier that epilepsy-related information concealment presented for parents and CWE when choosing to discuss epilepsy within the home.

Fear of Misinforming CWE in relation to Epilepsy

Parents spoke about their fear of misinforming CWE about their epilepsy when faced with explaining aspects of epilepsy to them, because they were often the primary source of information for CWE. This issue echoes back to initial difficulties at the point of diagnosis with parents not receiving what they perceived as adequate information relating to CWE's specific epilepsy type. A number of parents recounted difficulties they experienced when faced with epilepsy-related questions from CWE.

Difficulty Answering CWE's Questions

Fear of delivering misinformation in response to CWE's epilepsy-related questions was sometimes a daily struggle for parents. For many parents, the complexity of epilepsy, both in cause and prognosis, often contributed to making the terminology and information age-appropriate burdensome.

> *"We didn't have any information, you know, so I couldn't really explain it to her, you know, I don't want to say something that I wasn't sure …. You know, she would ask me a lot of questions so, I guess that"* - Mother of Taylor (aged 10 years)

To answer CWE's questions, parents had to be readily knowledgeable about their epilepsy condition; however, often parents relayed that they themselves felt under-informed regarding CWE's specific epilepsy diagnosis.

> *"I mean I suppose the way I've always looked at it is I don't have the answers for her, and I don't pretend to have them … so she'll chat away, and we'll chat away, and we'll kind of talk around it, and I can't say definitely it's all going to be ok, it's not going to be ok, you know"* - Mother of Anna (aged 15 years)

Lack of Parental Knowledge Regarding Epilepsy

Parents found it difficult to communicate directly with CWE because of their own limited knowledge of epilepsy. Parents revealed that they often relied on online information, which they acknowledged was potentially untrustworthy and scaremongering. The complexity and uncertainty of the information received at the time point of diagnosis presented a distinct barrier for parents both when learning about CWE's condition and choosing to communicate about epilepsy with CWE.

> *"You sometimes feel well your daughter has this, I should know about it but it's so hard to understand it… So being told about it, yeah it was scary because like, I mean, you'd be in hospital and see all the other children with broken legs and broken arms and you'd just do anything to have that problem rather than what we were being told because it was just unknown, we really didn't know"*
> - Mother of Ruth (aged 13 years)

A particular struggle for parents was the retrieval of information specific to CWE's diagnosis/seizure type. Parents often felt unsure of where to access reliable information and/or often found the information that they sourced difficult to understand; consequently, this created a barrier for parents in communicating about particular epilepsy-related issues.

> *"There was very little, I learned very little about dealing with the reality of epilepsy outside the medication, it was all about taking the medication, and indeed the medication has worked very well, but there was very little…very little around how to deal with a child and how to deal with a teenager now with epilepsy…you looked it up online and I suppose, from what I can see, you'll get the bare details of complex partial epilepsy, temporal lobe, etc. But every case seems to be different; it doesn't seem to be like talking about asthma or something, it seems to be very, very broad for getting information….We got information from them, we got information from the doctors, but most of it was very broad, and it wasn't necessarily relating to Anna's particular, what would you call, experience of it"*
> - Mother of Anna (aged 15 years)

Difficulty in Discussing Sensitive Unpredictable Epilepsy-related Issues

Parents found a number of epilepsy-related topics difficult to converse about with CWE. The four most frequently referred to topics were the seizure-free period and growing out of epilepsy (the possibility of CWE graduating from their epilepsy with age), epilepsy-related activity restrictions, epilepsy-related challenges yet to arise, and epilepsy disclosure. This challenge was particularly pertinent to parents of older CWE as a number of these conversation topics typically arose in adolescence.

Conversations about "the Seizure-free Period" and "Growing out of Epilepsy"

Parents spoke of the particular challenge that conversations relating to CWE's period of seizure freedom (i.e., the length of time since CWE's last seizure) presented. This was particularly relevant to parents of adolescents (aged 12 to 16 years) because of the future developments that lay ahead relating to key autonomy issues, such as driving, drinking alcohol, and career choices.

> *"It's a very big moral decision to get behind the wheel of a car, and that's something I kind of, kind of talk a little bit around, that, you know, when the time will come she'll have to make that decision herself but like it is a big moral decision. Do you get behind the wheel of a car? Yes, you've been two years seizure-*

free, but you could have a seizure at any time, and what happens if you kill someone or yourself or whatever and that, it's big, very, very big, very, very big. So I suppose those are the kind of things that are not particularly easy to talk about"

- Mother of Anna (aged 15 years)

The seizure-free period was seen as a particularly sensitive topic given the unpredictability of seizures and the possibility of circumstances changing suddenly (e.g., seizures occurring following a lengthy period of seizure freedom). Parents spoke of how they sometimes struggled to effectively relay to CWE that their seizure frequency was not something that they were accountable for.

"We are trying not to, we marked, we said, 'it is great, it is a year since you had a seizure.' And he said to me at one point, 'I am very proud of myself.' And I said, 'don't be proud of yourself because you have no control over it because that would mean if you had a seizure it would be something to be ashamed of.' I said, 'It is great, and we have had a great year, but if you have a seizure, we will just be thankful that we have had that year, and we move on from there.' So it is very sensitive" - Mother of Tony (aged 13 years)

Parents, particularly of the adolescent age group, found it challenging to communicate about the possibility of CWE graduating from their epilepsy with age, while still conveying honesty and transparency to CWE when uncertainty surrounded the condition.

"I have to, and I reduced the talk on epilepsy because the way I look on it is, now she knows this, they can't tell us in neurology if it's for life or if it's only a phase, so I do say that to her, I do say look we don't know if this is for life or not, so you just have to deal with what you have." - Mother of Marie (aged 13 years)

While parents tried to relay positive attitudes relating to lengthy periods of seizure freedom, challenges arose for parents when reaffirming to CWE that their epilepsy was not guaranteed to go away with age.

"So I suppose that was the hardest thing to talk to her about and to say look…we don't know, and it could still, it's under control, and it could still sort itself out, but there's no guarantee and that, so that time was difficult"

- Mother of Anna (aged 15 years)

Conversations about Epilepsy-related Activity Restrictions

Another barrier to epilepsy-related parent-child communication perceived by parents was that of activity restrictions. Parent-child dialogue relating to activities that CWE could not engage in due to their epilepsy often led to conflict.

> *"Now every so often you'll come across something that is a sharp shock , for example, fine weather, she went off out with her friends down the river, she came home first Friday thrilled with herself, 'we were down and we were off and it was very, very, deep, it was way out of our depth and we just jumped in' and I said 'but Anna, if you had a seizure' and she said 'what?' and I said 'Anna, you can't be down in the river out of your depth because if you have a seizure you will drown and your friends will try and save you and they will drown, you cannot do that'. So it was like a slap across the face for her, it never dawned on her; she's not walking around thinking 'oh my God I could have a seizure'. So of course we had a row because she's a teenager and I'm her mother, but like that was a sharp shock"*
>
> - Mother of Anna (aged 15 years)

Parents expressed particular difficulty in telling CWE that they could not engage in an activity with their peers.

> *"You try not to be blunt with him. Even at the moment he is interested in getting out his bike again, which he hadn't in about a year, but if you think he is going to have a seizure that day you would maybe make an excuse not to take the bike out and leave it to the following day. You would try not to sit him down and say, 'no we are not going for a cycle now, if you had a seizure.'"* - Father of Tadhg (aged 12 years)

Conversations about Epilepsy-related Challenges yet to arise

The majority of parents acknowledged that challenging conversations lay ahead as CWE entered later adolescence and adulthood. For example, issues such as driving, employment and drinking alcohol presented challenging topics to discuss and parents were concerned about potential difficulties in communicating about these future issues.

> *"Now it has, as I say, cropped up in the last year because she's now going into adulthood and the driving, the older children are all driving and that was a big*

thing for her, would she ever be able to drive and that was a huge thing for her and will I ever be able to drive and again, there's no definitive answer to that, you know, don't know" - Mother of Anna (aged 15 years)

The issue of challenges that are yet to arise in the lives of CWE caused concern for parents not only in terms of how to communicate with CWE about these challenges, but also in terms of what advice to impart to CWE. Parents sought to provide the utmost emotional support to CWE in their conversations.

"In terms of supporting her through what fears she may or may not have, in terms of the practicalities of when she gets to the stage where she's leaving school and she's doing courses or maybe she's looking for jobs, in terms of what she should disclose what she shouldn't disclose, all of that, if you like, I know nothing about any of that and as such you're kind of feeling your way as you're going along and hoping that, you know, you'll steer her in the right path if you like... In terms of whether we've dealt with it rightly or wrongly" - Mother of Anna (aged 15 years)

Some parents expressed their hope that these conversations would not have to occur, acknowledging the difficulty they may pose.

"I suppose we would never say, you can't do something because of your epilepsy. I think sometimes we should. Like he talks about he wants to join the army. The army is going to be out. Things like driving and I suppose because we just hope that they are going to go away someday" - Mother of Tadhg (aged 12 years)

Parents of CWE as young as 6 years at the time of interview were mindful that one day such topics would have to be broached with CWE, and mindful of the emotional impact such discussions could have on both CWE and themselves.

"So far there hasn't, but I suppose as she gets older and she starts asking about the longer term consequences, yes I will find that hard. I will still do it with her and I will still talk to her about it but I will find it hard because that will be upsetting for her as well" - Mother of Mandz (aged 6 years)

Conversations about Disclosure

Parents spoke of how a number of conversations with CWE centered on the topic of disclosing the condition to others outside of the family unit and how this presented a particular challenge

for them when choosing to talk about epilepsy within the home. Some parents felt that they should be selective as to whom they disclosed CWE's epilepsy to, in light of CWE's wish not to disclose their condition to others. In one incident, this created a significant stressor for the parent when trying to decide whether or not to disclose CWE's condition to her school teacher.

> *"She just was very disappointed, so I try and not to tell her [teacher], and Ruth took another seizure later on, and I didn't tell her [teacher] because Ruth begged me, 'cause she said it would only be torture"*- Mother of Ruth (aged 13 years)

This issue presented a challenge for a number of parents when communicating about epilepsy with CWE because, although these parents understood the potential implications of not disclosing CWE's epilepsy, many felt that they should respect CWE's wish to conceal their condition following conversations with them in which they requested this. Some parents spoke of how CWE sought reassurance about who was aware of their epilepsy.

> *"And then you know she's very conscious, like 'does anyone know?', 'don't tell this person'"* - Mother of Taylor (aged 10 years)

5.3.5 Parents' Perceived Enablers of Parent-Child Communication

Three themes pertaining to parents' perceived enablers of communicating about epilepsy with their CWE were identified. These themes include, pre-empting CWE's concerns about epilepsy, utilising humour in response to epilepsy, and encouraging CWE autonomy in relation to epilepsy (See Figure 5.3).

Pre-empting CWE's Concerns about Epilepsy

A number of parents attempted to pre-empt CWE's epilepsy-related concerns in order to alleviate any stress or anxiety that CWE may feel surrounding epilepsy-related events (e.g. – hospital appointments, EEG's, changes in medication). By pre-empting CWE's epilepsy-related concerns, parents were enabled to not only discuss epilepsy with CWE, but also to put them at greater ease prior to events such as epilepsy-related appointments or non-epilepsy-related activities. Pre-empting CWE's concerns behaved as a stimulus for conversation within the home.

> *"We sort of pre-empt things if we can. There about, before school broke up, they were going on a day trip down to Croke Park and I was thinking, hmm, and she*

*said oh Mammy and I'm going and I said of course you're going absolutely and the next thing I had the teacher on the phone, 'Hi' *laughs* I said yes, yes, would you like to come to Croke Park, I'd love to! *laughs* and she said I've asked Hermione would she mind if I asked you, I said Jesus what did she say, she said she'd love to yeah it's be grand… You know stuff like that; it works itself out, yeah. Normally if you don't make a big deal about something, you know, it sort of, it does"*

- Mother of Hermione (aged 13 years)

Utilising Humour in Response to Epilepsy

By incorporating humour into parent-child dialogue about epilepsy, parents felt greater enabled to discuss the condition whilst also limiting CWE worry and concern. A number of parents reported instances in which CWE were upset due to incidents external to the family home in which CWE felt they were stigmatised in light of their condition. For example, Anna's mother spoke of how Anna was asked to complete state examinations in a separate room in her school due to the possibility of her having a seizure during the exam. Using humour when discussing this issue with Anna enabled her mother to effectively talk about epilepsy with Anna, and also enabled Anna to view the incident in a less negative and impactful light.

"Another sharp shock she got was doing her Junior Cert, and the school contacted me and said look we feel that she should do it in a room on her own because if she has a seizure it'll disrupt the other pupils… that was pretty horrific. It had never dawned on Anna for one second that she could have a seizure during her Junior Cert… That was one hell of a sharp shock to be on her own. Now to be honest we kind of turned it around and we kind of joked about it and I said least you'll have a supervisor to yourself, I said you could be eating sweets, they'll give you biscuits, you'll be drinking tea and we made a bit of a giggle about it, but like it wasn't a giggle really, it was horrific, absolutely horrific" - Mother of Anna (aged 15 years)

By using humour in epilepsy-related conversations, some parents relayed that they were able to tone down the seriousness of a number of epilepsy-related events, thus reducing CWE concern.

Encouraging CWE Autonomy in relation to Epilepsy

In their interviews, parents relayed the practice of granting CWE a greater level of autonomy in relation to their condition as something which aided them to talk about epilepsy within the home. Greater independence was often afforded to CWE by giving responsibility to CWE to

adhere to their medication routines without supervision. A greater level of CWE autonomy when taking medication enabled a greater level of discussion relating to epilepsy between parents and CWE.

> *"Since Dave was ten, let him take a lot responsibility himself, he has to take his meds and he knows if he misses his meds he's going to have a seizure and he does, he really, really does. I'd still always text him 'have you taken your meds?' to remind him but he never would forget"* - Mother of Dave (aged 12 years)

5.3.6 Consequences of Parent-Child Communication for Parents

The primary consequence of parent-child communication about epilepsy for parents was the effect of feeling better informed about CWE's epilepsy following epilepsy-related engagements with them.

Feeling Greater Informed about CWE's Epilepsy

For parents, trying to understand CWE's epilepsy from their perspective was a benefit of talking about epilepsy with them. This enabled parents to get a greater sense of what epilepsy means to CWE.

> *"I think because we live with it every day it's quite normal, like it doesn't seem like a really big deal anymore, you know, and I'm trying to talk to her and understand what it feels like for her cause I don't really know. I definitely don't know … so that kind of stuff is really hard, really hard to tackle both for me and for her, so it's just learning how to manage all of that"* - Mother of Cee Lo (aged 8 years)

Not only was this a positive consequence of parent-child dialogue about the condition, a number of parents reported this to be a key motivator for them to engage in discussions about epilepsy with CWE; to gain a greater insight into how they live and cope with their condition on a day-to-day basis.

5.4 Summary of the Qualitative Findings

In this chapter, key findings relating to the communication strategies CWE and parents employed in relation to epilepsy were outlined. Specifically, the content, context, perceived barriers, enablers, and consequences of parent-child communication about epilepsy were presented.

CWE identified four communication strategies that they perceived families employed when discussing epilepsy, including; open, supportive, closed, and limited communication. These four strategies were echoed by parent participants, with a further two communication strategies discovered; communication avoidance, and influential communication. Considering the content of parent-child discussions, CWE and parents relayed similar topics throughout their interviews. CWE most notably mentioned five topics of epilepsy-related conversations; explaining epilepsy, epilepsy-related events such as hospital appointments and medication routines, seizure-freedom and graduating from epilepsy with time, how seizures manifested, and public perceptions of epilepsy. Parents relayed similar conversation topics with two additional issues that they discussed with CWE; offering/seeking reassurance in relation to epilepsy, and the disclosure of CWE's epilepsy condition to others. The contextual factors relating to talking about epilepsy within the home were largely the same for CWE and parents, focusing on the idea that; parent-child epilepsy-related communication is mostly spontaneous and not pre-planned, and a greater level of communication about epilepsy exists during times of increased epilepsy-related events, such as instances of higher seizure frequency or medication changes.

Though the reported content and context of parent-child epilepsy-related discussions were largely the same for CWE and parents, the reported barriers, enablers, and consequences of communication differed across groups. CWE perceived barriers for parent-child communication were; seeking normalcy, parental overprotection, parental reactions, and the restriction of activities. Parents also spoke about the barrier that the quest for normalcy presented, in addition to reporting a further five barriers, namely; coming to terms with epilepsy, the invisibility of epilepsy, information concealment, fear of misinforming CWE, and difficulty in discussing sensitive unpredictable epilepsy-related issues.

Substantially fewer enablers of epilepsy-related communication were identified by CWE and parents in comparison to the number of barriers reported. CWE-perceived enablers for parent-child communication were two-fold, including; parental knowledge about epilepsy, and the availability and willingness of parents to engage in epilepsy-related communication. Parents reported three perceived enablers; pre-empting CWE's epilepsy-related concerns, humour in response to epilepsy, and encouraging CWE autonomy. Finally, two consequences of talking about epilepsy for CWE were; being reminded of epilepsy-related restrictions, and having greater knowledge relating to their condition. A consequence of talking about epilepsy for parents was feeling greater informed about CWE's epilepsy. These qualitative findings will be discussed in further detail in the following chapter.

Chapter 6: Phase One: Qualitative Discussion

6.0 Introduction

In this chapter, the qualitative findings will be critically discussed according to the communication strategies employed by CWE and their parents when conversing about epilepsy, the content of epilepsy-related discussions, the context in which CWE and parents generally talk about epilepsy, the barriers and enablers to effective epilepsy-related communication, and the consequences of talking about epilepsy in the home for CWE and their parents. In this chapter the perspectives of CWE and their parents are discussed separately in order to ascertain any differences in the execution, perception of, and potential impact of epilepsy-related communication. The strengths and limitations of this phase will be outlined, followed by the implications of this qualitative phase for the subsequent quantitative phase of this mixed methods study.

6.1 Epilepsy-related Communication Strategies

The present study identifies a number of communication strategies at play within families of CWE, ranging from open and free-flowing parent-child communication to closed and infrequent communication about epilepsy within the home. To date, studies involving families living with childhood epilepsy have focused on parent reactions to epilepsy (Austin et al., 2008), parental coping strategies (Shore, Austin, Huster, & Dunn, 2002), and parents' attempts to effectively manage the family system in light of an epilepsy diagnosis (Austin et al., 2002; Mu & Chang, 2010); however, epilepsy-related communication strategies in families of CWE have until now remained unaddressed. Consequently this study presents a unique contribution to understanding the various strategies that CWE, and their parents, employ when communicating about epilepsy in the home. Four communication strategies were reported by CWE in the present study; open, supportive, closed, and limited communication surrounding epilepsy.

An open communication strategy was described by CWE as one in which parents provided frequent and open discussion in relation to epilepsy, which helped them to cope with their condition and any issues epilepsy presented in day-to-day life. Increased coping abilities and greater perceptions of parental trustworthiness in response to open parent-child communication strategies have been previously reported amongst children living with diabetes (Faulkner & Chang, 2007), asthma (Kurnat & Moore, 1999), inherited genetic conditions (Metcalfe, Coad, Plumridge, Gill, & Farndon, 2008), and in the adjustment of adopted children (Brodzinsky,

2006). The present findings provide novel evidence of these psychosocial benefits in a CWE sample.

Supportive communication strategies in response to epilepsy were also relayed by CWE. CWE reporting a supportive communication strategy indicated that their communication with parents was multi-faceted, with CWE seeking psychological support from parents whilst also seeking to gain epilepsy-related information from them. These CWE felt supported by their parents when faced with times of uncertainty relating to their epilepsy, and felt greater enabled to effectively self-manage their epilepsy. Previous research has found that a more supportive and cohesive family environment predicts positive outcomes within children with chronic illnesses (Barlow & Ellard, 2006), including greater overall adjustment (Ferro, Avison, Campbell, & Speechley, 2011; Wu, Follansbee-Junger, Rausch, & Modi, 2014) and medication adherence (DiMatteo, 2004). Within the present study, CWE who perceived a supportive communication strategy learned to view their condition in a more positive light following epilepsy-related engagements with their parents. Parents can serve as cheerleaders and-esteem builders for chronically-ill children, however, little is known about children's health beliefs and how these may reflect those of their parents (DiMatteo, 2004). Though CWE's perceptions of epilepsy-related stigma have been previously shown to mirror those of their parents (Austin et al., 2004), the qualitative findings of this study present novel evidence supporting the use of supportive communication (i.e. – esteem-building, and encouragement), in the development of positive epilepsy-related attitudes amongst CWE.

Not all CWE reported the adoption of open and/or supportive communication strategies relating to epilepsy within the home. Closed (whereby CWE never discussed the condition), and limited communication (whereby CWE discussed epilepsy with little frequency and/or depth, and parent-child communication about epilepsy was at times carefully selective) strategies were also described by some CWE.

Closed parent-child communication strategies have been previously reported in the research literature in response to other childhood chronic illness, including diabetes (Dashiff, Hardemen, & McLain, 2008), and asthma (Evans et al., 2001). However, no studies have previously reported investigating the adoption of closed parent-child communication strategies surrounding epilepsy and how these are perceived by CWE. CWE in the present study who perceived a closed communication strategy within their family reported that they generally never spoke about epilepsy with their parent(s). Previous studies propose that 1 in 5 families of CWE

endorse unhealthy levels of family functioning (Herzer et al., 2010), and are less likely to openly discuss issues as a family compared to families in the general population (Tzoufi et al., 2005). Even when compared with families living with other chronic illnesses, such as asthma, families of children with epilepsy demonstrate poorer family functioning (Austin, 1988; Mendes, Crespo, & Austin, 2016). Therefore, the existence of closed communication relating to epilepsy within families of CWE is not wholly surprising. However, the rationale behind the adoption of closed communication strategies amongst CWE (i.e. – the barriers to effective parent-child communication about epilepsy perceived by CWE) is of particular interest to this study. These communicative roadblocks are discussed in further detail in section 6.4.

Limited epilepsy-related communication strategies were also reported by CWE in the present study. Many CWE relayed that their condition was spoken about in an infrequent, context specific and sometimes judicious manner. The adoption of a limited communication strategy by CWE in this study appears to relate to clinical characteristics (i.e. seizure type and frequency) and the visibility of the condition within the home, in that CWE did not feel epilepsy-related communication was necessary when their epilepsy was not a feature in everyday life due to a greater time span since diagnosis or more controlled seizures.

While some previous reference has been made to a potential link between less frequent parent-child discussions surrounding epilepsy and greater seizure control previously (Hodgman et al., 1979), this is the first study to explicitly document CWE experiences of limited communication surrounding epilepsy with their parents. Interestingly, some CWE who perceived a limited communication strategy were cognisant of the often judicious manner by which parents chose to talk about their condition. As with an array of other childhood chronic illnesses, parents of CWE occupy the role of informer to their child in relation to their condition (Hanai, 1996; McNelis et al., 2007; Hirfanoglu et al., 2009; Jantzen et al., 2009). In the present study adopting a limited communication strategy was linked with CWE believing that parents were withholding information relating to their epilepsy whilst not conversing about certain condition-related topics, thus leaving them frustrated and often confused with regard to their epilepsy. Although previous research has found that CWE feel under-informed about their condition (Hirfanoglu et al., 2009), the present study has identified for the first time the potential relationship between communication strategies, and CWE feeling under-informed and dissatisfied with the level of epilepsy-related information that they have received. Although CWE did not explain their reasons for adopting a limited communication strategy with their parents, parents provided

further detail surrounding the adoption of limited communication strategies about epilepsy. These findings are discussed below.

The communication strategies described by parents echoed those relayed by CWE with the same four approaches adopted; open, supportive, closed, and limited communication about epilepsy. However, two further communication strategies were reported by parents; avoidance of and influential communication.

Many parents sought to foster open and supportive communication strategies with CWE. Parents who sought to facilitate an open communicative environment in response to epilepsy were explicitly cognisant of the impact of their discussions with CWE. Parents who adopted an open approach often referred to this as a conscious decision made at the outset of CWE's epilepsy diagnosis in order to encourage positive CWE perceptions of epilepsy, and less feelings of burden relating to the condition. This adoption of an open communication strategy in order to protect CWE from negative illness attitudes relayed by parents in the present study has also been echoed in previous studies in parental adjustment to childhood cancer (Grootenhuis & Last, 1997) and points to a key reason for parents to choose to openly talk about epilepsy with CWE.

Parents also felt that offering epilepsy-related support to CWE, by way of a supportive communication strategy surrounding epilepsy, helped to reduce feelings of loneliness and uncertainty for CWE at the time of diagnosis and during periods in which epilepsy presented a challenge in day-to-day life. It is widely documented that the diagnosis process presents a challenging and stressful time for families of children with chronic illness, particularly parents (Cohen, 1993; Cousino & Hazen, 2013; Cole & Reiss, 2013). Parents adopting a supportive communication strategy indicated that they adopted this strategy at the onset of the epilepsy diagnosis and that this created a precedent for how they coped with the condition. Supportive communication surrounding created a greater sense of reassurance for CWE and parents in times of uncertainty, such as greater seizure frequency or an increase in antiepileptic medication. Indeed, Rait et al. (1992) have asserted that high levels of family support are imperative to positive coping during acute phases of child illness, indicating that a supportive communication strategy may result in more positive outcomes for CWE and parents. Parents adopting this form of epilepsy-related communication not only relayed the benefits for CWE, but also spoke of how such parent-child communication enabled them to cope better with CWE's epilepsy. This mutual-benefit supports previous research that highlights the "buffering effect" of supportive communication for parents (Grootenhuis & Last, 1997), and how open and supportive

communication can enable parents and children to discuss related matters with ease as they arise (Canam, 1993; Metcalfe et al., 2008).

As with CWE's reports of parent-child communication, parents also relayed the adoption of closed communication strategies whereby they never spoke about epilepsy with CWE. Parents were more forthcoming with information regarding why epilepsy was not spoken about within the home, citing; a lack of knowledge relating to CWE's condition, a desire to normalise epilepsy and encourage CWE not to dwell on their condition, and non-disclosure of epilepsy with others external to the family context as primary reasons for not discussing epilepsy with CWE. Lack of parental knowledge caused parents to be reluctant to engage in epilepsy-related dialogue with CWE due to the difficult prospect of being unable to answer any epilepsy-related queries CWE may have. This finding is supported by previous literature highlighting parents' need-for-information regarding their child's epilepsy and parental feelings of being ill-equipped to effectively manage condition-specific queries from their child (Jantzen et al., 2009; McNelis et al., 2007; Claflin & Barbarin, 1991). Some parents reported that they did not discuss epilepsy in order to discourage CWE from talking about epilepsy with other non-family-members. This was due to the parent's perception of the potential negative social connotations attached to epilepsy in the public domain and fear of CWE encountering epilepsy-related stigma. Scambler and Hopkins (1986) have previously identified the issue of parental perceptions of epilepsy-related stigma when faced with communicating about the condition with others external to the family unit (i.e. – disclosing epilepsy). However, the utilisation of closed communication strategies by parents found in the present findings raises the novel issue of perceived stigma within the family unit and its potential to limit epilepsy-related communication between parents and CWE. Further barriers to effective communication about epilepsy perceived by parents of CWE will be discussed in section 6.4.

Limited communication strategies were reported by parents whereby epilepsy was talked about to a lesser extent and in particular contexts or circumstances. Often, parents maintaining limited communication perceived their CWE's epilepsy as "mild" and therefore not warranting in-depth and/or frequent related conversations. Limited communication was largely based on the visibility of CWE's epilepsy within the home; with less communication occurring during times of fewer seizures and less perceived epilepsy-related disruptiveness. Although Joachim and Acorn (2000a) have posited that the decision to communicate about a condition *with others* is often based on the visibility of the illness, this study also highlights the influence of illness-visibility within the family context.

Findings revealed that some parents evaded epilepsy-related communication with CWE, thus engaging in an avoidant communication strategy. Avoidant communication strategies were used by parents in a conscious attempt to monitor the level of condition-related information they imparted to CWE as a means of protecting CWE from epilepsy-related anxiety or worry. Although parents adopting an avoidant communication strategy did engage in some epilepsy-related dialogue with CWE, these parents largely avoided the initiation of such discussions. Parents relayed actively avoiding communicating about epilepsy with CWE to both; reduce levels of epilepsy-related worry and anxiety for CWE, and in response to their own discomfort and fears relating to the condition. Unlike limited communication strategies, parents engaged in avoidant communication not due to a lack of clinical manifestations of epilepsy but in order to minimise CWE's epilepsy-related worry or concern. The approach of avoiding epilepsy-related discussions with CWE was viewed as protective by parents; the evasion of talking about the condition within the home enabled parents to shield CWE from any potentially concerning or burdensome information.

Jantzen et al. (2009) previously demonstrated this parental prerogative to protect CWE from having to deal with their epilepsy; however, a dearth of research literature exists examining the impact of this communication avoidance on CWE. Parents' own attitudes towards epilepsy also led them to engage in communication avoidance surrounding the condition. Some parents relayed how their own feelings of grief and concern would result in them not wishing to engage in epilepsy-related dialogue with CWE. Greater levels of anxiety exist amongst parents of CWE (Williams et al., 2003) and the potential for seizure-related anxiety and fear to be relayed to CWE via parent-child interactions has been noted (Ronen et al., 1999). Parents within the present study stated avoiding parent-child communication about epilepsy in order for their fears to not be conveyed to CWE. Deliberately choosing to avoid communication with chronically-ill children about condition-related topics that may cause worry or future condition-related challenges yet to arise is not uncommon. Indeed, Sartain, Clarke, and Heyman (2000) suggest that parents of chronically-ill children often do not talk about the future with them in order to avoid their children thinking of negative outcomes. It has also been documented previously that parents of CWE often perceive themselves as key role-models and protectors of CWE with regard to their condition (McNelis et al., 2007). However, to the author's knowledge, this is the first study to show that protectiveness in parents of CWE may be manifested as avoidant communication with CWE.

Though some parents avoided communicating about epilepsy with CWE, other parents adopted an influential communication strategy when engaging in epilepsy-related conversations with their CWE. In using an influential communication strategy parents worked to propel how CWE might perceive their condition. This influential communication strategy was regarded in both optimistic and undesirable terms. Optimistically, parents relayed to CWE the positive aspects of their condition. In undesirable terms, parents' negative perceptions of epilepsy were relayed to CWE via parents' downbeat attitudes, beliefs and behaviours. Findings from the present study demonstrate cases in which parents actively conveyed to their CWE the stigma that encircles their condition. Indeed, as Scambler and Hopkins (1986) have alluded to in their research, CWE's first perceptions' of epilepsy-related stigma may be within parent-child interactions, a process which they have coined "stigma-coaching". It is recognised within the literature that children's perceptions of their parents' views are thought to influence their own self-related beliefs and feelings (Goldin, 1969). Parents' views of epilepsy may be effectively relayed to CWE via influential communication strategies surrounding the condition. Drawing on the overarching concept of Bronfenbrenner's (1979) social-ecological systems theory, it may be argued that parent-child communication plays a fundamental role in CWE's emotional wellbeing. Furthermore, how parents opt to communicate with children may also inform elements of their child's psychosocial wellbeing (Manian, Papadakis, Strauman, & Essex, 2006). With regard to epilepsy specifically, parents' perceptions of epilepsy have been shown to impact upon CWE's epilepsy-related attitudes (Austin & Huberty, 1993; Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000). Parent-child communication relating to epilepsy-related stigma is therefore a crucial influence on CWE's perception of their condition.

The qualitative findings relating to the communication strategies adopted by CWE and their parents suggest that strategies were largely parent-led, with parents informing the way in which epilepsy was talked about within the family context. This is especially apparent in parents voicing avoidant and influential communication strategies, two approaches that were not echoed by CWE. An integral component of these two approaches was parents' wish to lead how CWE perceived their condition; by avoiding epilepsy-related communication to reduce CWE epilepsy-related worry, and by engaging in communication to promote specific epilepsy-related attitudes. Open and supportive communication strategies were best received by CWE and parents, leading to both feeling greater assured in relation to epilepsy. Though parents engaged in limited communication strategies in order to encourage a greater sense of normalcy for CWE, CWE

conversely reported that such strategies left them feeling frustrated and under-informed in relation to their condition. These findings suggest that conversations between CWE and parents should be opened up in order for CWE and parents to learn what level of communication they each perceive as desirable and most beneficial to their coping and wellbeing. The present study offers a novel contribution to the research literature by outlining what and how different communication strategies are employed in families living with childhood epilepsy, and the factors influencing their use.

6.2 Context of Epilepsy-related Communication

Previous research has focused on parent-child illness-related interactions in contexts such as when liaising with HCPs (Tates & Meeuwesen, 2001; Nova, Vegni, & Moja, 2005), however, no studies have specifically focused on parent-child communication about epilepsy within a family context. Findings from the present study highlight two aspects relating to the context in which CWE discussed epilepsy and epilepsy-related issues. Firstly, epilepsy-related communication occurred spontaneously, that is, the majority of CWE spoke of how the topic of their epilepsy would come up of its own accord in day-to-day conversations and talking about epilepsy was never a predetermined aim. Secondly, for many CWE, seizures acted as a catalyst for parent-child conversations about epilepsy. Talking about epilepsy occurred more frequently in times when CWE had poor seizure control. CWE experiencing more frequent seizures were likely to also experience a greater level of hospital appointments or medication changes, provoking a greater level of epilepsy-related discussion between CWE and parents. Therefore, epilepsy-related communication between CWE and parents typically surrounded the occurrence of epilepsy-related events.

Parents outlined similar contexts in which they usually talked about epilepsy and epilepsy-related issues with CWE. For parents; epilepsy-related communication was not pre-planned, and, as in CWE's view, epilepsy-related communication was related to seizure control. Parents spoke of how they engaged in more parent-child epilepsy-related dialogue when CWE were experiencing a greater number of seizures and related events (such as hospital appointments or medication changes). In contrast, when seizures were infrequent or absent, the condition become invisible and parents felt that there was less of a need to talk about epilepsy.

To the author's knowledge this is the first study to investigate the contexts in which parents and children living with childhood epilepsy talk about epilepsy with each other. CWE and parents highlighted similar situations in which they talked about the condition, that is, that epilepsy-

related events caused a greater level of communication about the condition. The influence of epilepsy-related events occurring in the lives of CWE on epilepsy-related communication brings to light the issue of condition visibility within the home. Joachim & Acorn (2000a) have emphasised the impact of condition invisibility on communication external to the family (i.e. – disclosure practices), whereby condition invisibility afford persons the ability to not communicate (or conceal) their illness. Though previous research has highlighted how the invisibility of a condition can impact on communication external to the family, for the first time the present study imparts novel evidence demonstrating how condition invisibility (in this case heightened by periods of seizure freedom) also plays a role in parent-child communication.

6.3 Content of Epilepsy-related Communication

The content of epilepsy-related conversations engaged in by CWE and their parents provides insight into what parent-child dialogue centred on. CWE conveyed the content of their epilepsy-related conversations across five themes; epilepsy-related events, the possibility of CWE growing out of epilepsy, gaining explanations of epilepsy, the manifestation of CWE's seizures, and public perceptions of epilepsy.

One of the most commonly reported topics of epilepsy-related conversation amongst CWE interviewees was that of epilepsy-related events, citing conversations relating to their seizures, hospital appointments, and medication routines as paramount in day-to-day life. In keeping with CWE's discussions of these epilepsy-related events, the topic of their period of seizure freedom and the possibility of graduating from their epilepsy condition was commonly discussed. Indeed, the issue of seizure freedom is unique to CWE given the unpredictability and differential prognosis of an epilepsy diagnosis and was particularly relevant for CWE in the adolescent age group. While a unique consideration for CWE, seizure freedom time-period is not an unexpected communication topic for adolescents with epilepsy given the uncertainty they often face regarding how their seizure control could affect issues of importance in early adulthood such as school examinations (Brodie & French, 2000), driving (Salinsky, Wegener, & Sinnema, 1992), and career choices (Appleton, Chadwick, & Sweeney, 1997). However, findings of the present study show that CWE were comfortable and hopeful when discussing the possibility of growing out of their condition with their parents, indicating that these conversations enabled them to understand the process of seizure freedom, and potential medication withdrawal, with greater ease.

Understanding different aspects of their condition was of fundamental importance to CWE in the present study. A large number of CWE sought to learn about their epilepsy via explanations provided by parents. Families of children living with a chronic illness are instrumental in creating an environment in which the child can effectively learn about his/her condition (Eiser, 1993). As Young et al. (2003) have previously alluded to, parents in particular often undertake the role of communication broker, providing easier-to-understand explanations and breaking down complex terminology for their child's comprehension. Epilepsy is a complex neurological condition that may be difficult to understand, especially for a child (Jantzen et al., 2009). CWE in the present study sought information relating to what epilepsy is and what caused epilepsy, usually at the outset of their epilepsy diagnosis.

CWE were concerned about public perceptions of epilepsy and seizures. In terms of the content of parent-child communication about epilepsy, this issue manifested in two ways for CWE; conversations about the manifestation of CWE's seizures and how they may appear to others, and how others in wider society might perceive epilepsy. Regardless of type, seizures can be disruptive to social interactions and, depending on their specific manifestations, can be aesthetically unpleasant (Jacoby et al., 2005). CWE discussed the manifestations of their seizures with their parents as they felt that their parents would provide them with a frank and honest description, regardless of their aesthetic. Public perceptions of epilepsy and epilepsy-related stigma were also spoken about within the home of many CWE. Regarding society's perceptions of epilepsy, the social prognosis of epilepsy may be less hopeful than the clinical one (Jacoby et al., 2005) and a historical prejudice against epilepsy, perpetuated by a lack of information, still exists in wider society (Baumann, Wilson, & Wiese, 1995; Aydemir, Kaya, Yildiz, Oztura, & Baklan, 2016). CWE in the present study, particularly in the adolescent age group, acknowledged negative stereotyping and spoke of their wish for public awareness surrounding epilepsy.

Parents raised similar topics of epilepsy-related conversation including; explaining epilepsy to CWE, epilepsy-related events, the possibility of CWE growing out of epilepsy, the manifestation of CWE's seizures, and public perceptions of epilepsy. A further two conversational contents not relayed by CWE were described by parents; reassuring CWE about epilepsy, and the issue of disclosing epilepsy to others outside the family unit.

As primary information providers to CWE, parents reported that they were mindful of the depth of explanations they gave to CWE; only providing explanations of epilepsy to the point of CWE

satisfaction for fear of too much epilepsy-related knowledge causing unnecessary worry. Parents' descriptions of epilepsy were dependent on CWE age and seizure type, with the majority of parents feeling confident in gauging the level of information desired by CWE. Whilst providing such explanations, parents were also cognisant of the terminology used when referring to CWE's epilepsy. The terminology used was largely age-dependent, with parents of younger CWE using developmentally-comprehendible terms created by them usually at the time of initial seizure onset such as "zoning out" or "fizzies". Parents of older CWE tended to utilise more medical terms such as "seizures" and "epilepsy". The terminology used relating to child chronic illness can have a lasting impact on how children perceive and conceptualise their condition (Koopman, Baars, Chaplin, & Zwinderman, 2004), thus, considering how parents of CWE use terminology is important. The majority of parents chose to adopt medical-like terminology, such as "seizures" or "epilepsy", with many stating the benefits of a straight-forward approach when conversing with CWE. However, parents also spoke of the journey they faced when coming to terms with both the condition and the use of the word "epilepsy". Epilepsy is a chronic condition that also harbours a social label (Arnston, Droge, Norton, & Murray, 1986), with the application of the label "epileptic" separating those with epilepsy from others in society (Jacoby et al., 2005). Parents' recognition of the potentially stigmatising attributes of the word "epilepsy" caused them initial difficulty in using the term, with some describing it as a "coming out" process. This struggle supports previous research relating to the difficulty the term "epilepsy" presents in familial conversations (Mulder & Suurmeijer, 1977; Ronen et al., 1999; Mu, 2008). Parents spoke of how they were accepting of CWE's epilepsy-related language use and their discretion to use what terminology they wished when talking about their condition.

Parents spoke of how they sought to provide CWE with reassurance in relation to the condition and how this dominated much of the epilepsy-related dialogue they engaged in. Previous research suggests that CWE are in need of a greater level of support than children without epilepsy, with 1 in 5 CWE reporting an insufficient level of support and reassurance from their family (Hirfanoglu et al., 2009). Parents in the present study relayed how they aimed to provide CWE with reassurance in relation to a number of epilepsy-related issues including; seizure control, activity restrictions, and treatment paths. Parents also relayed instances of seeking reassurance from CWE in relation to their epilepsy in order to alleviate their own worries and anxiety. CWE's recognition of parents' worry in relation to their epilepsy has been previously noted by Moffat et al. (2009); however, to the author's knowledge, this is the first study to

reveal that in their conversations with their children parents actively seek reassurance from their CWE about his/her condition.

Similar to CWE reports, a predominant theme of the content of parents' conversations with CWE was epilepsy-related events. Parents reported that talking about planned hospital or clinic appointments with CWE prior to the event aided in alleviating any anxiety CWE may have experienced; communication in this instance was a preventative course of action. Conversations relating to previous epilepsy-related events, such as seizures or medication changes, allowed CWE to consolidate emotions relating to these events. Fivush (1994) explains that parent-child discussions may provide the first opportunity for children to experience their personal and emotional meaning of an event, as children are often unable to reflect on these emotions at the time the event is occurring. This is particularly relevant to parent child discussions centring on seizures that CWE may not be able to wholly recall. Though Fivush (1994) suggests positive outcomes for children following communication about previous events with parents, a small number of parents in this present study spoke of how conversations, particularly relating to medication adherence, could initiate parent-child conflict and in some cases cause CWE upset. This was particularly pertinent to parents of CWE in the adolescent age group whose CWE were beginning to seize responsibility of their medication routines.

Despite CWE considering talking about possible graduation from their epilepsy as a positive experience, the majority of parents of adolescent CWE reported that the concept of growing out of epilepsy presented a sensitive and challenging issue for them to discuss. The difficulty parents faced was largely attributed to the need to discuss moral issues surrounding seizure freedom, such as the decision to drive. In a small number of cases parents also reported difficulty surrounding CWE coming to view epilepsy as a lifelong condition, despite parents themselves facing this realisation earlier in CWE's diagnosis. Parents' reactions and care during difficult condition-related conversations could play a crucial role in CWE's response to medication adherence and later personal outcomes (Ziegler, Erba, Holden, & Dennison, 2000). Parents were largely cognisant of this and talked about a need for transparency at all times when discussing future epilepsy-related concerns with CWE. Similarly, parents reported that the manifestation of seizures was a major concern of some older CWE (aged 11 – 16 years), stating that CWE came to them for descriptions of how their seizures appeared. Parents of older CWE spoke of how they considered explaining what occurred during their seizures, with a number of parents reporting uncertainty over how to approach this issue. Some parents even relayed to CWE that witnessing seizures caused them fear. This finding is consistent with previous

research that found evidence of parents relaying seizure-related fear to CWE during parent-child interactions (Ronen et al., 1999). Parents of CWE often face concern when choosing what education approach to take in relation to CWE's epilepsy (Mu, 2005) and how to explain the condition's social ramifications (Jantzen et al., 2009). The present study offers new insights into condition-related conversational topics that may present difficulty for parents of CWE. Findings suggest that parents are in need of guidance and advice specifically in relation to how to explain seizure manifestations to CWE in a way that will lessen any anxiety CWE may experience. Further challenging aspects of talking about epilepsy for both parents and CWE are discussed in section 6.4.

When referring to conversations relating to public perceptions of epilepsy, parents pointed to instances of epilepsy in the media as a positive catalyst for parent-child communication about the condition. Although public awareness campaigns relating to epilepsy have proved beneficial in the reduction of epilepsy-related stigma in society (DeBoer, 2002; Paschal et al., 2007), some parents in this study were faced with explaining epilepsy-related stigma to CWE following their encounter of differential treatment because of their condition. Consequently, similar to CWE, parents also suggested the potential need to increase public knowledge surrounding epilepsy, with a number of parents relaying the need for more high-profile "role models" with epilepsy in the media. However, previous studies have noted a difficulty in locating such celebrity figures (Krauss, Gondek, Krumholz, Paul, & Shen, 2000).

Interestingly, parents talked about disclosing epilepsy to others outside of the family as a communication topic; however this was not raised by CWE. This may be due to a greater awareness by parents of the implications of disclosing CWE's epilepsy diagnosis both at present and on entering early-adulthood. Conversations relating to disclosure centred on CWE's disclosure wishes, explaining to CWE why disclosure may be a necessary process and, in some cases, encouraging CWE to disclose their epilepsy to peers in order to lessen personal burden. Numerous examples of parent-child communication relating to disclosure were provided by parents, corroborating research that suggests that disclosure is not a single event and rather a process of telling some about the condition whilst choosing to conceal it from others (Kılınç & Campbell, 2009). Notwithstanding this, parents spoke of their concern of CWE encountering prejudice on disclosure of their epilepsy to others. Perhaps this is not surprising considering that disadvantageous judgements continue to be made about individuals with epilepsy, with examples demonstrated in education (Gallhofer, 1984), employment (Rätsepp, Õun, Haldre, & Kaasik, 2000), and insurance (Jacoby & Jacoby, 2004). However, parents in this study sought

not to relay such concerns to CWE when discussing their opportunities and wishes to disclose or conceal their condition.

Findings unearthed relating to the content of epilepsy-related discussions among CWE and parents highlight that CWE primarily discuss epilepsy to gain information or knowledge relating to their condition, and parents engage in epilepsy-related conversations in order to provide CWE with information and psychological and emotional support. Epilepsy-centred discussions ranged from future projected epilepsy-related issues (such as the possibility of growing out of epilepsy), to matters surrounding the public's awareness of epilepsy (such as how seizures appear and whether or not to disclose the epilepsy diagnosis to others). These findings emphasise the dependency of CWE's and parents' epilepsy-related conversations on the context in which they occur, i.e. – many topics of conversation solely arose amongst CWE and parents due to a contextual catalyst, such as an epilepsy-related event or epilepsy being highlighted by the media. The potential barriers and enablers of parent-child conversations about epilepsy will be discussed further in the following sections.

6.4 Barriers to Epilepsy-related Communication

Though CWE and their parents spoke of how and when they chose to converse about epilepsy within the home, barriers to effective communication about the condition did exist for both parties. Factors impeding epilepsy-related conversations varied between CWE and parents of CWE, with parents identifying more barriers to discussing epilepsy than CWE. These barriers are discussed below, firstly from CWE perspectives, followed by barriers apparent for parents.

This study identifies four key barriers for CWE when choosing to talk about their epilepsy condition with their parents, these were: communication impeding normalcy, parental overprotection, parental reactions to epilepsy-related communication, and restriction of activities as a consequence of epilepsy-related communication.

Communication about epilepsy within the family home was reported by many CWE to be a barrier to leading, what they perceived to be, a normal life. CWE reported that talking about epilepsy with their parents made them feel different from peers and siblings, thereby disrupting their quest for normalcy within the family environment. Findings from this study support previous evidence suggesting that families living with childhood chronic illness acknowledge the condition as a threat to a normal lifestyle (Knafl & Deatrick, 2002), and

children living with long-term conditions, including epilepsy, constantly grapple with balancing feelings of normality with feelings of difference (Lambert & Keogh, 2015). Messages young people receive about what defines "different" and "normal" are largely informed by what is sanctioned by their social world as desirable (Elliott, Lach, & Smith, 2005). As Elliott et al. (2005) alluded to in their investigation, it is important to note that such senses of "normality" are socially constructed, therefore, the level of parent-child dialogue engaged in by children may impact on them in different ways depending on general family functioning. Prior to the current investigation, little was known about how families' striving for normalcy and avoiding difference might impact on communication processes within families living with childhood epilepsy, nominally promoting communication avoidance. Findings from the present study reveal that utilising parent-child dialogue about epilepsy as a normalising strategy does not necessarily yield positive outcomes for CWE, but often promotes feelings of differentness and reminds CWE of the restrictions that their condition can impose on them. These communication practices, coupled with CWE's underreporting of symptoms (such as seizures) and suboptimal self-management (such as medication non-adherence) to avoid dialogue with their parents that might result in parents impeding CWE's participation in social activities, and could potentially impact directly on both the physical and social functioning of CWE.

Other reasons that caused CWE to often limit epilepsy-related engagements with their parents or completely avoid communication about their epilepsy in the home were: parents' reactions during discussions about epilepsy and related issues, parental worry, and parents "making a big deal" about epilepsy. Findings from the present study support previous research that identified parent worry in relation to epilepsy as a significant concern for CWE (Moffat et al., 2009). CWE in this study felt that by opening communication about epilepsy, they would escalate parental concern and worry in relation to their epilepsy condition. This in turn, would lead to a lowered sense of autonomy. The concept of parental worry impeding CWE communication and the novel finding of CWE perceptions of parents "making a big deal" about epilepsy highlights the importance of parental reactions to epilepsy and the impact the reaction has on epilepsy-related communication engaged in within the family context. This finding further emphasises the unique and influential position parents hold in relation to not only CWE's perceptions of their condition, but also to CWE's decision to engage in a dialogue about epilepsy with their parents.

Reassuring parents in relation to seizures and other epilepsy-related issues (such as medication routines) was seen as imperative for a number of CWE in order to reduce the level of heightened supervision and overprotection that parents engaged in. The majority of CWE in the adolescent age group found their parents need for vigilance and supervision to be an annoyance. This finding reinforces previous research that has found parental supervision as burdensome to CWE (Hirfanoglu et al., 2009), with many CWE deeming their parents to be overprotective (McEwan et al., 2004). Additionally, a number of CWE strove to eliminate restrictions imposed on them by parents by not disclosing fully the details of epilepsy-related events such as seizures. Previous research has indicated that a greater level of parental knowledge relating to epilepsy can result in parents imposing fewer restrictions on CWE (Hirfanoglu et al., 2009). Future research is needed to examine the association between parental knowledge of epilepsy and the level of parental overprotection/restriction of CWE social participation.

Considering the barriers to epilepsy-related communication reported by parents of CWE, this study provides unique insights into parents' views and experiences of the challenging aspects of communicating with CWE about their epilepsy condition and epilepsy-related issues. Findings build on and substantiate the limited prior evidence on the difficulties parents experience when engaging in dialogue with CWE about their epilepsy (Mu & Chang, 2010; Coulter & Koester, 1985). Parents experience a breadth of communicative barriers ranging from: coming to terms with epilepsy, the normalisation of epilepsy, the invisibility of epilepsy, the restriction of information transmission to CWE in an attempt to minimize CWE worry, and the fear of misinforming CWE as a consequence of limited parental knowledge about the epilepsy diagnosis. These barriers are in addition to those associated with discussing sensitive unpredictable epilepsy-related topics about which parents often lack information. Many of these barriers impacted on parents' ability to openly engage in parent-child dialogue in the home.

Parents described lowering levels of family interaction related to epilepsy in response to their perceived need to normalise the condition for CWE and eliminate any feelings of differentness CWE may have in relation to their epilepsy. Often, in their endeavour for normality and uniformity, parents opted to not discuss epilepsy and epilepsy-related issues with CWE. This low level of discussion was undertaken as a normalising strategy by parents, and supports previous research in the area of childhood chronic illness (Hanai, 1996; Jantzen et al., 2009; Knafl, Breitmayer, Gallo & Zoeller, 1996). Despite this, little is

known about the positive or negative impact that lowering epilepsy-related communication may have on CWE and their perceptions of epilepsy. Although previous research with CWE has highlighted their dissatisfaction with the limited level of epilepsy-related communication within the home (Lewis & Parsons, 2008), future research specifically tailored to measuring the impact of silence surrounding epilepsy within the home is needed. Also, although communication within the family context has been coined as a key coping mechanism in family adaptation to childhood epilepsy (Tzoufi et al., 2005; Herzer et al., 2010), parents in this study also spoke about the challenges of communicating with CWE when originally coming to terms with CWE's epilepsy diagnosis. Although parents spoke of communicating about the diagnosis of epilepsy sometimes together or with a partner, parents grappled with discussing the condition both with CWE and with others external to the family unit around the time point of diagnosis. Research examining communication external to the family context, such as the disclosure practices of children living with epilepsy and their parents also warrants investigation. Indeed, a recent systematic review revealed limited evidence existed on the disclosure behaviours of CWE and their parents (Benson et al., 2015). Further research is also examining parent and CWE perspectives of disclosing an epilepsy diagnosis to others external to the family unit (Benson, Lambert, Gallagher, & Shahwan, 2015).

Parents in this study were cognisant of the level of epilepsy-related information they imparted to their CWE and the impact this information might have on their CWE's level of worry and concern related to epilepsy. This corroborates previous research that found that parents identified themselves as role models who, through their attitudes and behaviours, could shape their CWE's perceptions of epilepsy (McNelis et al., 2007). Data indicating dilemmas on parental fear of misinforming CWE and difficulty in answering their CWE's questions were directly related to parent's lack of knowledge about epilepsy; and more specifically their CWE's specific epilepsy classification. Despite the recognition that inherent complications and uncertainty often surround the diagnosis process for CWE epilepsy and their families (Austin, 1988), data in this study demonstrated that many parents did not feel that their information needs in relation to understanding their CWE's condition were met. For instance, parents reported feeling either under-informed or unable to cope with the amount of information received from healthcare professionals at the point of diagnosis. This left parents devoid of confidence in explaining the complexity of epilepsy to their CWE. This has important implications for CWE because parents are often

considered to be the prime agents to transmit information about their condition to them. As reported in previous research, parents' own need for information may not only result in closed communication surrounding epilepsy and epilepsy-related issues but can also cause parents to impose greater restrictions on their CWE's social activities and afford their CWE less autonomy (Lewis & Noyes, 2013).

A novel finding of this study, unique to epilepsy, and specific to communication barriers within the context of epilepsy, is that parents reported difficulties in discussing sensitive unpredictable issues such as the seizure-free period and "growing out of" childhood epilepsy. The impact that parent-child dialogue relating to these topics can potentially have on CWE's psychosocial wellbeing was a major concern for parents of CWE. The unpredictability and uncertainty surrounding these issues presented a particular challenge for parents when faced with communicating about these topics with CWE. Not wanting to cause unnecessary worry or anxiety in relation to particular issues such as medication-associated difficulties and SUDEP often resulted in parents withholding information from their CWE. SUDEP, in particular, presents a highly important topic in epilepsy-related communication for CWE and their parents (Camfield & Camfield, 2005). Further research is needed to ascertain the impact of related discussions on CWE's perceptions of their condition, and ways in which to facilitate open communication about these topics.

CWE and parents face similar barriers to parent-child dialogue about epilepsy in the form of seeking normalcy, reducing worry, and discussing epilepsy-related activity restrictions. The trajectory of CWE's epilepsy gave rise to a greater number of barriers for parents when choosing to discuss epilepsy, facing challenges in both coming to terms with epilepsy following the epilepsy diagnosis, and discussing future epilepsy-related challenges that may arise for CWE. In contrast, CWE indicated that parents' reactions to epilepsy-related dialogue presented a distinct barrier to such parent-child discussions. This suggests parents may play a role in creating greater comfort for CWE to talk about epilepsy with them by tailoring their reactions to epilepsy-related communication.

6.5 Enablers of Epilepsy-related Communication

A number of enabling factors exist for parent-child epilepsy-related communication from CWE and parents' perspectives. However, CWE and parents relayed differing perspectives on what they found helpful in initiating and engaging in conversations about epilepsy.

Two key enablers for CWE when choosing to talk about epilepsy with their parents were: a greater level of parent knowledge surrounding epilepsy, and the availability/willingness of parents to discuss epilepsy. Trust in parents' level of epilepsy-related knowledge encouraged CWE to confide in them with any worries or concern they may have about their epilepsy, and approach them to learn about their condition further. This finding provides support for previous research in which education-focused family interventions had positive outcomes for greater family functioning (Austin et al., 2002). Though a lack of parental knowledge relating to epilepsy has been highlighted previously as a struggle for parents of CWE when faced with imparting epilepsy-related information (Jantzen et al., 2009; McNelis et al., 2007), previous research has largely focused on parent reports. To the author's knowledge, this is the first study to highlight the importance of parent epilepsy-related knowledge in facilitating parent-child communication from a CWE perspective. By providing parents of CWE with greater epilepsy-information specific to their child's diagnosis, CWE will feel greater enabled to talk about epilepsy with their parents, thus opening up channels of communication about epilepsy within the home. The positive consequences of enabling open communication about epilepsy between parents and CWE are discussed in section 6.6.

The perceived availability and willingness of parents to talk about epilepsy was also relayed by CWE as an enabler of parent-child dialogue about epilepsy. A small number of CWE reported that they felt that parents did not have the time or desire to talk about their condition. This finding may have important implications for CWE when choosing to approach parents to talk about their epilepsy. CWE in the present study were likely to engage in parent-child dialogue about epilepsy when their parents had relayed their availability and willingness to do so. It is therefore important for parents to remain cognisant of relaying encouraging attitudes to CWE in relation to communicating about epilepsy.

Enablers of epilepsy-related communication for parents differed from those highlighted by CWE. For parents, enablers included; pre-empting CWE's epilepsy-related concerns, the use of humour during epilepsy-related conversations, and encouraging CWE's autonomy in relation to their epilepsy.

By adopting parental strategies of pre-empting epilepsy-related concerns CWE may have prior to an epilepsy-related event, such as an upcoming hospital appointment, parents felt that they were able to raise the topic of epilepsy with ease and also reduce any anxiety CWE may experience in light of this concern. Similarly, it was hoped by a number of parents that the use of

humour would detract from any negative or burdensome feelings CWE had in relation to their condition and enable them to talk about epilepsy with greater ease. It is widely acknowledged within the literature that CWE experience greater levels of anxiety than children in the general population (Williams et al., 2003; Vazquez & Devinsky, 2003; Stevanovic, Jancic, & Lakic, 2011). Furthermore, parental reactions during epilepsy-related communication have been found to impact upon the level of anxiety CWE experience, with parental reactions of fear and distress shown to contribute to greater anxiety in CWE (Williams et al., 2003; Pellock, 2004). Parents utilising a more positive and comforting approach, as demonstrated here via pre-emptive behaviour, not only enabled parents to discuss epilepsy with CWE but may result in more positive outcomes for CWE in the form of lessened anxiety.

Parents of adolescent CWE in particular felt that by affording CWE responsibility and independence with regard to their condition they could facilitate a greater level of parent-child communication about epilepsy. Development of autonomy has previously been highlighted as a significant issue for adolescents with epilepsy (McEwan et al., 2004). By responding to issues of autonomy in a proactive way, parents created opportunities to talk about epilepsy with CWE. Parents encouraged CWE independence by relinquishing control of medication routines and encouraging a greater level of CWE interaction in engagements with HCPs. Numerous studies have investigated the issue of autonomy and clinician-parent-child triadic communication in children with chronic illness (Tates & Meeuwesen, 2001; Sawyer & Aroni, 2005; Cahill & Papageorgiou, 2007), suggesting that parents affording children with greater autonomy during engagements may promote greater adherence to medication regimes. However, the influential role of autonomy in facilitating parent-child communication about epilepsy is a novel finding of this study.

Though the factors enabling parent-child communication about epilepsy differed according to CWE and their parents, all five of the enablers identified (from both CWE and parent perspectives) focus upon parental behaviours. Having a greater knowledge about CWE's epilepsy, conveying an availability and willingness to discuss epilepsy with CWE, pre-empting CWE's epilepsy-related concerns, using humour during engagements about epilepsy, and affording CWE a greater level of autonomy in relation to their epilepsy have been pinpointed as key mechanisms by which parents can enable a greater level of communication about epilepsy within the home. The systematic review conducted at the outset of the present study highlighted no significant facilitators to parent-child dialogue about epilepsy. With previous research highlighting parental concern about how to encourage CWE to talk to them about their condition

(Coulter & Koester, 1985), this qualitative data provides a valuable contribution in identifying a number of factors that parents felt enabled them to engage in dialogue with their CWE. These findings have significant implications regarding the formation of an effective family communication intervention for families living with childhood epilepsy, suggesting that effective interventions should perhaps focus upon parental behaviours in the facilitation of epilepsy-related communication.

6.6 Consequences of Epilepsy-related Communication

Though positive impacts of parent-child epilepsy-related communication have been previously demonstrated for CWE (Austin et al., 2002; Nicholas & Pianta, 1994; Moffat et al., 2009; Jantzen et al., 2009), few studies have sought to explicitly examine the consequences of communication about epilepsy for parents of CWE. Addressing this gap was important because examining the consequences of parent-child communication about epilepsy increases understanding of the ways in which communication level and type may result in optimal outcomes for CWE and their parents.

For CWE a negative consequence of parent-child communication was being reminded of the restrictions their epilepsy imposes on them and their "different" status. In contrast, feeling more knowledgeable about their condition was considered a positive consequence. Considering firstly the negative consequence of parent-child communication about epilepsy for CWE; the issue of normalcy seeking in children with chronic illnesses (Knafl et al.,1996; Sartain et al., 2000; Knafl & Deatrick, 2002) and epilepsy specifically (Elliott et al., 2005) has been documented previously. For some CWE in this study talking about epilepsy impeded their sense of normalcy as it sometimes served to remind them of activities they were unable to take part in. For this reason, these CWE were unwilling to engage in parent-child dialogue about epilepsy and reported that they did not like to talk about their condition. Parent-child communication relating to activity restrictions has also been highlighted as a challenging issue for parents of CWE within the present study. To the author's knowledge, this is the first documented example of parent-child epilepsy-related communication resulting in negative consequences for CWE, with no previous studies uncovering this relationship.

Conversely, a positive consequence of parent-child communication about epilepsy for CWE was feeling greater informed about epilepsy following such discussions. This finding adds to previous evidence suggesting that greater parent knowledge about epilepsy results in positive outcomes for CWE, such as; CWE perceiving greater levels of family functioning (Austin et al.,

2002), CWE experiencing fewer activity restrictions (Hirfanoglu et al., 2009), and less CWE frustration in relation to perceived parental overprotection (McEwan et al., 2004).

Unlike CWE who identified positive and negative consequences of parent-child communication about epilepsy, parents only spoke about positive consequences, namely feeling greater informed about epilepsy. Indeed, as has been previously discussed, parents' lack of information relating to epilepsy can create a number of roadblocks to effective parent-child dialogue (Jantzen et al., 2009; McNelis et al., 2007). Findings from the present study indicate that a greater level of parent-child dialogue relating to the condition could result in parents learning more about their CWE's specific experience of epilepsy from their perspective. Interestingly, greater parental knowledge about epilepsy has also been identified as an effective enabler of parent-child communication about epilepsy within the findings of the present study. These findings suggest that a bidirectional positive association exists between parents' epilepsy-related knowledge and parent-child communication about epilepsy; with parental knowledge enabling parent-child communication, and parent-child communication enhancing parental knowledge.

Insights gained from the qualitative findings suggest that though the consequences of parent-child communication about epilepsy relayed by parents appear overwhelmingly positive, this may not be the case for CWE. The fact that CWE can experience positive and negative consequences of parent-child communication raises a question in relation to the optimum approach to parent-child communication about epilepsy, and whether communication surrounding particular epilepsy-related issues, such as activity restrictions, may result in more negative outcomes compared to other epilepsy-related discussions. Further research is required to determine exactly what consequences CWE may experience following parent-child communication about epilepsy, and what factors may influence this.

6.7 Strengths and Limitations of the Qualitative Phase

The qualitative phase of this mixed methods study offers a distinct contribution to the limited research on parent-child epilepsy-related communication from the perspectives of both CWE and their parents. Despite this strength, some limitations exist. The most notable limitation of this qualitative phase was that the majority of participants were CWE (or parents of CWE) with refractory epilepsy recruited from a tertiary referral route (the neurology department of a major paediatric hospital). Furthermore, for the purpose of this phase, the experiences of CWE and parents of CWE with no significant comorbidities were sought (in order to investigate parent–child dialogue that was purely related to epilepsy as opposed to communication that may be

related to another condition). In order to achieve this, the sample for this first phase was recruited via a neurology department in a national children's hospital and through a national epilepsy advocacy organization. Due to the varying seizure characteristics of the CWE interviewed and the recruitment paths chosen, the sample of this phase cannot be considered representative of all CWE and parents of CWE. Indeed, in line with qualitative research, the intention of this first phase was not to generalize to the larger population but rather to develop an in-depth understanding of parent-child epilepsy-related dialogue within the home (Shenton, 2004). To enable consideration to be given to the transferability of the findings to other settings, by understanding the context of the particular characteristics of the sample for this first phase, a detailed description of demographic and geographic boundaries of the study was provided. Future qualitative research investigating the potential impact of gender, clinical, and contextual factors on parent-child epilepsy-related communication is recommended.

Finally, the findings of this qualitative phase were derived according to the communication strategy employed within the home at the time of interview. However, previous literature has shown that the management of communication strategies can fluctuate over the course of a child's illness, with the period of diagnosis being a particularly influential time in the creation of a communication pattern surrounding the condition (Young et al., 2003). Mu (2008) argues that the health-to-illness transition experienced by children living with epilepsy and their families at the time of diagnosis presents alterations in parent-child interactions as parents react to the psychological stress inherent in their child receiving a diagnosis of epilepsy. Future research should endeavour to employ longitudinal methods in order to investigate parent-child communication across the trajectory of childhood epilepsy.

6.8 Implications of the Qualitative Phase for the Quantitative Phase

The findings of this qualitative phase highlight a number of issues warranting further examination within the subsequent quantitative phase. Whilst the qualitative phase has allowed for an in-depth exploration of parent-child communication about epilepsy, identifying key elements of communication strategies, the content and context of, barriers and enablers, and consequences of such dialogue, a quantitative assessment is important to ascertain the extent to which these are used and experienced by CWE and their parents. Exploring the consequences of communicating about epilepsy with CWE identified positive outcomes for parents, for example feelings of greater knowledge about CWE's condition following such conversations. However, CWE reported positive and negative consequences of talking about epilepsy with their parents;

some CWE felt greater informed about their condition, however, some CWE were also reminded of the restrictions their condition imposed on them following epilepsy-related communication within the home. The variation of these consequences and outcomes warrants a greater examination of how epilepsy-related communication may impact on CWE's and parents' psychosocial wellbeing.

In response to the findings and proposed interpretations of the qualitative phase of this study, a number of key variables were identified for closer examination in phase two of this mixed methods study. In order to examine quantitatively how CWE and parents engage in parent-child dialogue about epilepsy, the quantitative phase specifically examines; the context and content of, reasons for and against, barriers and facilitators of, and emotions following parent-child communication about epilepsy, from both CWE and parent perspectives. In order to examine the consequences of parent-child communication about epilepsy, a number of pre-validated measures assessing CWE and parent psychosocial wellbeing were included, spanning the following variables; perceived stigma, illness-attitudes, self-perception, health-related quality of life, social support, need for epilepsy-related information, and need for epilepsy-related support.

6.9 Conclusions of the Qualitative Phase

This first qualitative phase highlights the unique experiences of CWE and their parents when engaging in epilepsy-related dialogue within the home. CWE and parents did not convene to a prevailing way of communicating about epilepsy, with a variety of communication strategies reported - often depending on the perceived level of impact that epilepsy had on family life (e.g. – CWE's seizure frequency at the time of interview). Communication surrounding epilepsy was largely parent-led, with parents' communicative behaviours setting a precedent for CWE by implicitly identifying roles and directives for support and coping.

Despite the majority of CWE and parents engaging in some form of communication surrounding the condition, talking about epilepsy was not without its challenges. Openness and ease of epilepsy-related communication were threatened by issues such as normalcy seeking, the invisibility of epilepsy as a condition, a fear of causing worry, and a lack of epilepsy-related knowledge. Interestingly, parents reported more barriers, than their CWE, to effective epilepsy-related communication with CWE, perhaps due to their typical role as communication facilitator within the home. A number of effective enablers were also identified in the form of greater parental knowledge about epilepsy and offering of CWE autonomy. Varying consequences of

parent-child communication about epilepsy, both positive and negative were uncovered. It is of crucial importance to examine these barriers, enablers, and consequences further in order to ascertain what form of communication may result in optimal psychosocial outcomes for CWE and their parents. This information may play a key role in the development of an effective family-based communication intervention for CWE and their parents.

Chapter 7: Phase Two: Quantitative Method

7.0 Introduction

A detailed account of the method employed in the second quantitative phase of this mixed method study will be provided in this chapter. Specifically this chapter will detail the aims and hypotheses for phase two, the recruitment processes, sample selection, ethical considerations, and data collection and analysis strategies.

7.1 Quantitative Study Design

The second phase of this mixed-method study involved a quantitative cross-sectional survey.

7.2 Phase Two Aims and Hypotheses

The aim of phase two was to quantitatively assess the relationship between parent-child dialogue about epilepsy and a number demographic, clinical, and psychosocial variables.

The objectives of this phase were:

- To investigate the relationship between parent-child communication strategies and demographic variables, including; parent/CWE age, parent/CWE gender, and parent education level.
- To assess the relationship between parent-child communication strategies and clinical variables, including CWE's; seizure type, seizure severity, seizure visibility, seizure frequency, and family history of epilepsy.
- To assess the relationship between parent-child communication strategies and psychosocial variables for CWE; including, perceived stigma, illness attitudes, health-related quality of life, perceived social support, self-perception, need for epilepsy-related information and support, and perceived satisfaction with the level of epilepsy-related information they have received.
- To assess the relationship between parent-child communication strategies and psychosocial variables for parents'; including perceived stigma, response to CWE's illness, perceived social support, perceived impact of epilepsy on CWE and the family, need for epilepsy-related information and support, and perceived satisfaction with the level of epilepsy-related information they have received.

The specific hypotheses to be examined in the quantitative phase are outlined below. These hypotheses were developed in accordance with the available literature surrounding parent-child illness-related communication and psychosocial outcomes.

The hypotheses for CWE specific data include:

1. Open communication strategies in CWE will be associated with lower levels of perceived epilepsy-related stigma amongst CWE, whereas closed communication strategies in CWE will be associated with higher levels of perceived epilepsy-related stigma amongst CWE.
2. Open communication strategies in CWE will be associated with positive illness attitudes amongst CWE, whereas closed communication strategies in CWE will be associated with negative illness attitudes amongst CWE.
3. Open communication strategies in CWE will be associated with higher CWE self-esteem across six self-perception domains; scholastic competence, social competence, athletic competence, physical appearance, behavioural conduct and global self-worth, whereas closed communication strategies in CWE will be associated with lower CWE self-esteem across these six self-perception domains.
4. Open communication strategies in CWE will be associated with a greater CWE perceived health-related quality of life across five domains; interpersonal/social consequences of epilepsy, worries and concerns relating to epilepsy, intrapersonal emotional issues experienced as a result of epilepsy, the degree to which CWE wished to keep epilepsy a secret, and the desire for a sense of normality experienced by CWE with epilepsy, whereas closed communication strategies in CWE will be associated with lower CWE perceived health-related quality of life across these five domains.
5. Open communication strategies in CWE will be associated with higher levels of social support, particularly from parental figures, whereas closed communication strategies in CWE will be associated with lower levels of social support, particularly from parental figures.
6. Open communication strategies in CWE will be associated with a lesser need for information and support relating to their epilepsy, whereas closed communication strategies in CWE will be associated with a greater need for information and support relating to their epilepsy.
7. Open communication strategies in CWE will be associated with greater satisfaction with the level of information they have received relating to their epilepsy, whereas closed

communication strategies in CWE will be associated with less satisfaction with the level of information they have received relating to their epilepsy.

The hypotheses for parent specific data include:

8. Open communication strategies in parents will be associated with lower levels of perceived epilepsy-related stigma, whereas closed communication strategies in parents will be associated with higher levels of perceived epilepsy-related stigma amongst parents.
9. Open communication strategies in parents will be associated with positive perceptions/responses to the CWE's condition, whereas closed communication strategies in parents will be associated with negative perceptions/responses to this child's condition.
10. Open communication strategies in parents will be associated with parents perceiving a lesser impact of epilepsy on the family, whereas closed communication strategies in parents will be associated with parents perceiving a greater impact of epilepsy on the family.
11. Open communication strategies in parents will be associated with parents perceiving a lesser impact of epilepsy on CWE themselves, whereas closed communication strategies in parents will be associated with parents perceiving a greater impact of epilepsy on CWE.
12. Open communication strategies in parents will be associated with higher levels of parent perceived social support, whereas closed communication strategies in parents will be associated with lower levels of parent perceived social support.
13. Open communication strategies in parents will be associated with parents expressing a low need for information and support, whereas closed communication strategies in parents will be associated with parents expressing a high need for information and support in relation to CWE's epilepsy.
14. Open communication strategies in parents will be associated with greater satisfaction with the level of information they have obtained relating to their CWE's epilepsy, whereas closed communication strategies in parents will be associated with less satisfaction with the level of information they have obtained relating to their CWE's epilepsy.

7.3 Phase Two Sample

In this second phase, 47 CWE (aged 8-18 years) and 72 parents of CWE participated. Further information relating to the sample for this phase is detailed in section 8.1 of Chapter 8.

7.3.1 Selection Criteria

The inclusion criteria for CWE participants were: CWE aged between 8 and 18 years with a diagnosis of epilepsy (idiopathic, cryptogenic, or symptomatic epileptic syndromes) over 6 months and a prescription for anti-epileptic drugs (AEDs). CWE presenting with an intellectual disability or developmental delay and any additional significant medical conditions (other than epilepsy) were excluded.

The inclusion criteria for parent participants were that they were the parent of a CWE.

Due to the readability of some of the included pre-validated psychometric instruments, and to ensure a full understanding of the questionnaire content, CWE below 8 years of age were excluded. The upper age range for CWE participant eligibility was extended to 18 years for phase two because during phase one of the study it emerged that some CWE remained in receipt of paediatric services up to the age of 18 years. CWE were required to have a diagnosis of epilepsy over 6 months in order to allow for the family to establish a communication strategy, or not, around epilepsy in the home. This criterion was included as many of the questions within the questionnaires required CWE and parents to draw upon their experiences of talking about epilepsy within a family context.

7.3.2 Ethical Considerations

Ethical approval was granted from Dublin City University Research Ethics Committee (See Appendix K1), Temple Street Children's University Hospital Research (TSCUH) Ethics Committee (See Appendix K2), HSE North East Area Research Ethics Committee (See Appendix K3), and St. James's Hospital/Adelaide and Meath National Children's Hospital (SJH/AMNCH) Research Ethics Committee (See Appendix K4).

The ethical issues of informed consent, confidentiality and data protection were considered. Each survey pack distributed to potential participants contained: a cover letter, CWE and parent information sheets, CWE and parent questionnaires, CWE and parent resource sheets outlining available supports, and two stamped and addressed envelopes (one for parent and one for CWE) for questionnaire returns (See Appendices L1 – L8). Informed consent was sought from all

CWE and parent participants at the outset of the questionnaire, therefore, return of questionnaire implied consent for all participants concerned. All questionnaires were anonymous on their return to the researcher. All potential participants were advised in this regard within the information sheet contained in the survey pack.

7.3.3 Recruitment

Potential participants were recruited via two recruitment routes; 1) Paediatric and/or Neurology Hospital Units (TSCUH, Our Lady of Lourdes Hospital, and St. James's Hospital) and 2) Epilepsy Ireland.

Route 1: Paediatric and/or Neurology Hospital Units

Potential CWE and parents who met the inclusion criteria for the study were informed about the study during epilepsy clinic hours by nominated clinicians at each site. If families expressed an interest in the study they were referred to me and I provided them with further information about the study and sought their participation. A survey packet (i.e. cover letter, information sheets, consent forms, questionnaires, and support information) was distributed by post to CWE and their parents as they were highlighted by the nominated clinicians (See Appendices L1 – L8). If CWE and their parents decided to participate in the study they either; completed the questionnaires at home and returned them directly to me in the stamped and addressed envelope provided, or completed the questionnaire online via the Qualtrics survey platform (Qualtrics, Provo, UT). These two completion formats were offered for the purpose of facilitating greater response rates.

Route 2: Epilepsy Ireland (The Irish Epilepsy Association)

Potential participants were recruited via advertisements on the Epilepsy Ireland website and in the Epilepsy Ireland members' newsletter (See Appendix L9). Additionally, a communications officer within Epilepsy Ireland contacted potential participants via telephone to inform them of the research study. In both cases, my contact details were included and/or provided so that parents who wished to participate could contact me directly regarding any queries or concerns they had. Participants were provided with information regarding the study and were offered the opportunity to either: 1) complete the questionnaire online via the Qualtrics survey link provided in the newsletter or on the EI website; or 2) request a hard copy through the project email. For those requesting hard copies of the questionnaires, I took the name and address of the interested

parties and posted out the survey packet with a stamped and addressed envelope to facilitate return of the questionnaires.

For all recruitment routes, in the case of hard copy completion, two follow-up 'thank you' letters were distributed at two separate time frames (at two-week and four-week intervals following initial survey pack postage) to thank those who completed and returned the questionnaire and as a reminder and repeat invitation for those who had not yet completed and returned questionnaires to do so if they still wished to participate in the study (See Appendices L10 and L11).

7.4 Questionnaires

The questionnaires for CWE (Appendix L5) and parents (Appendix L6) were developed from an amalgamation of existing valid and reliable age appropriate child and parent instruments (discussed later in section 7.4.1 and 7.4.2 respectively) and a newly devised questionnaire (the Parent-Child Communication about Epilepsy Questionnaire) that aimed to investigate parent-child communication specific to CWE and their parents.

In the absence of an existing measure to specifically assess parent-child communication surrounding epilepsy in families of CWE, the Parent-Child Communication about Epilepsy Questionnaire was developed. Two versions were designed; a version for CWE aged 8 – 18 years, and a version for parents of CWE aged 8 – 18 years. In order to adequately assess parent-child communication employed by CWE and their parents, a number of items were developed to investigate fully the strategies, frequency, context, content, barriers, enablers, and consequences of parent-child dialogue about epilepsy. These items were developed based on the background literature available and the findings from the first phase of this mixed method study. This measure, along with the additional measures included within the CWE and parent questionnaires, is described below.

7.4.1 CWE Questionnaire Materials

The materials for inclusion in the CWE questionnaire are described below. These are divided into three categories: 1) parent-child communication variables, 2) psychosocial variables, and 3) demographic and clinical variables.

CWE-Reported Parent-Child Communication Variables

Parent-Child Communication about Epilepsy Questionnaire – CWE Version

The CWE version of the Parent-Child Communication about Epilepsy Questionnaire consists of 40 items across six subcategories measuring CWE's perspectives on various aspects of parent-child communication about epilepsy. Specifically, these subcategories consist of the following; context of parent-child communication about epilepsy (8 items), content of parent-child communication about epilepsy (9 items), CWE's reasons for communicating about epilepsy with parent(s) (5 items), CWE's reasons against communicating about epilepsy with parent(s) (5 items), barriers and enablers of parent-child communication about epilepsy (6 items), and CWE's emotions following parent-child communication about epilepsy (7 items).

Parent-Child Communication Level

This parent-child communication variable was designed by the researcher to capture the level of parent-child communication about epilepsy from a CWE perspective. Two aspects of this variable exist; Mother-Child Communication Level, and Father-Child Communication Level. The "Mother-Child Communication Level" variable sought to capture the perceived level of dialogue about epilepsy between mothers and CWE from a CWE perspective. The "Father-Child Communication Level" variable sought to capture the perceived level of dialogue about epilepsy between fathers and CWE from a CWE perspective. This measure incorporated the scoring key; 1 = Not at all, 2 = A little, 3 = Somewhat, and 4 = Very Much. CWE also had an option to mark this as "Not Applicable" in which case a score was not calculated. Higher scores indicate that CWE engage in a greater level of communication with mothers and fathers respectively.

Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy

This parent-child communication variable was designed to capture the level of affect felt by CWE following parent-child communication about epilepsy within the home, from a CWE perspective. Two aspects of this variable exist; Positive Affect of Parent-Child Communication about Epilepsy and Negative Affect of Parent-Child Communication about Epilepsy.

The "Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy" variable was developed from the seven items pertaining to "feelings" within the CWE Parent-Child Communication about Epilepsy Questionnaire.

"Talking about epilepsy with my Mum or Dad makes me feel… happy/ sad/ worried/ brave/ embarrassed/ different/ special"

CWE were asked to rate each feeling according to the scoring key; 1 = No, 2 = Yes. Negative feelings (Sad, Worried, Embarrassed, and Different) were subsequently reversed scored. A Principle Component Analysis (PCA) was performed on these seven items. Before PCA was carried out on the subscale data, its suitability for PCA was assessed by performing a Kaiser-Meyer-Oklin analysis and running Bartlett's Test of Sphericity. The Kaiser-Meyer-Oklin (KMO) value was 0.62, exceeding the recommended value of .5 for a satisfactory factor analysis to proceed (Hinton, Brownlow, McMurray, & Cozens, 2004) and all of the Measures of Sampling Adequacy (MSA) produced via the anti-image correlation matrix were above the recommended value of 0.7 (Pett, Lackey, & Sullivan, 2003). The data's suitability for PCA was also supported by Bartlett's Test of Sphericity (Bartlett, 1954) achieving statistical significance.

A two-component solution accounting for 57% of the variance was found to be optimal on the basis of scree curve analysis, eigenvalues, variance accounted for, and meaningful interpretation. The rotated PCA solution for the seven items revealed the presence of two components with eigenvalues exceeding 1, with the items "sad", "worried", "embarrassed" and "different" loading onto component 1 (explaining 35% variance), and the items "happy", "brave" and "special" loading onto component 2 (explaining 57% variance) (See Table 7.1).

Table 7.1: ***Rotated Component Matrix for the Solution for the "Feelings" 7-items***

	Component	
	1	**2**
Happy		.804
Sad	.635	
Worried	.733	
Brave		.654
Embarrassed	.687	
Different	.750	
Special		.618

Considering the content of the two component loadings, one containing predominantly positive affect for CWE following parent-child communication about epilepsy ("happy", "brave" and "special"), and one containing predominantly negative affect ("sad", "worried", "embarrassed", and "different"), the decision was made to split this "Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy" variable into "Perceived Positive Affect of Parent-Child Communication about Epilepsy" and "Perceived Negative Affect of Parent-Child Communication about Epilepsy" respectively.

The "Perceived Positive Affect of Parent-Child Communication about Epilepsy" variable captures the level of positive affect experienced by CWE following communicating about epilepsy with their parent(s). In order to increase the reliability of the scale from a Cronbach's alpha of .54 to a Cronbach's alpha of .66, the "Special" item was removed from the analysis. The decision to remove the "Special" item from the "Perceived Positive Affect of Parent-Child Communication about Epilepsy" variable was not only based on reliability analyses, but also on concerns relating to the word "special" representing an affect/emotion. The word "Special" could also potentially have connotations of "undesirable differentness", providing a greater rationale for its exclusion from this analysis. The "Perceived Positive Affect of Parent-Child Communication about Epilepsy" variable was calculated by the sum of the two included items. Higher scores indicate a greater positive affect for CWE following communicating with their parents about epilepsy.

The "Perceived Negative Affect of Parent-Child Communication about Epilepsy" variable captures the level of negative affect experienced by CWE following communicating about epilepsy with their parent(s). This variable was calculated by the sum of the four included items. A reliability analysis of the four items revealed a reliable Cronbach's Alpha of .68. Higher scores indicate a greater negative affect for CWE following communicating with their parents about epilepsy.

Revised Family Communication Patterns Instrument (RFCP)

The RFCP is a valid and reliable 23 item measure of family communication norms across a wide age range including children (Ritchie & Fitzpatrick, 1990). This instrument measures two orientations; concept-orientation and socio-orientation.

The 10 items relating to 'concept orientation' measure parental encouragement of conversation and the open exchange of ideas and feelings. In a concept oriented environment, children are encouraged to develop and express autonomous opinions and are said to be less susceptible to influence and focus on informational cues within the message. Concept orientation is associated with a greater level of open communication within the family context. Higher scores indicate a lesser affinity to a family environment which is concept oriented, i.e. – higher scores reflect a lower level of open communication.

The 13 items relating to 'socio-orientation' measure the use of parental power to enforce the child's overt conformity to the parent. In a socio-oriented environment, children are more

susceptible to influence from outside sources and tend to focus on source characteristics of a message. Socio-orientation is associated with a greater level of closed communication (i.e. – a lack of communication) within the family context. Higher scores indicate a lesser affinity to a family environment which is socio-oriented, i.e. – higher scores reflect a greater level of open communication. This measure has demonstrated good validity and reliability (Koerner & Fitzpatrick, 2002), with a reported Cronbach's alpha of 0.92 (concept-orientation) and 0.71 (socio-orientation) in the present study.

CWE-Reported Psychosocial Variables

Child Stigma Scale (CSS)

The CSS is an 8-item scale that assesses perceived stigma in CWE (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). Items developed for this scale relate to feelings of being different, perceptions of others and items specific to disclosure of epilepsy condition. CWE rate how often they feel or act in ways described in the eight items on 5-point scale from 1 (never) to 5 (very often). A higher score reflects greater perceptions of stigma. This scale has shown good validity and internal consistency reliability (Austin et al., 2004) with a coefficient alpha of 0.92 in the present study.

Child Attitude toward Illness Scale (CATIS)

The CATIS is a 13-item scale that assesses children's positive and negative feelings about having a chronic condition (Austin & Huberty, 1993). Four items are rated on a 5-point scale of bipolar adjectives and nine items ask children to rate along a 5-point response scale how often they feel positive or negative about having their chronic condition (i.e., epilepsy). Higher scores reflect a more positive illness attitude. This measure has been demonstrated to have good validity and internal consistency reliability (Heimlich et al., 2000) with a coefficient alpha of 0.86 in the present study.

Self-Perception Profile for Children (SPPC)

The SPPC is a 36-item questionnaire that assesses children's self-esteem across five specific domains, namely; scholastic competence, social acceptance, athletic competence, physical appearance, and behavioural conduct, in addition to global self-worth (Harter, 1985a). The questionnaire items are divided into six items within each subscale. Items are rated on a 4-point scale from 1 (least perceived competence/adequacy) to 4 (greatest perceived competence/adequacy). This instrument has been shown to have good validity and internal

consistency reliability (Harter, 1985a) with the present study reporting alpha coefficients for all six subscales as 0.93 (scholastic competence), 0.87 (social acceptance), 0.92 (athletic competence), 0.92 (physical appearance), 0.84 (behavioural conduct) and 0.93 (global self-worth).

Health-Related Quality of Life Measure for CWE (CHEQOL)

The CHEQOL is a 25-item scale with five subscales measuring interpersonal/social consequences (5 items), worries and concerns (5 items), intrapersonal/emotional issues (6 items), epilepsy my secret (8 items) and quest for normality (5 items) (Ronen, Streiner & Rosenbaum, 2003). Children are presented with two statements and decide which one is more like them, for instance, "*some kids with epilepsy say kids won't play with them BUT other kids with epilepsy say other kids always play with them*". Children then decide if the statement is "*sort of true*" or "*really true*" of them. This scale has demonstrated good validity and internal consistency reliability (Ronen et al., 2003), with the present study reporting alpha coefficients for all five subscales as; 0.89 (interpersonal/social consequences), 0.77 (worries and concerns), 0.77 (intrapersonal/emotional issues), 0.76 (epilepsy my secret), and 0.71 (quest for normality).

Social Support Scale for Children and Adolescents (SSSCA)

The SSSCA is a 24-item rating scale with four subscales which assess children's perceptions of social support from four sources (i.e. parents, teachers, classmates, and friends) (Harter, 1985b). Similar to Ronen et al.'s CHEQOL measure (2003), children are presented with two statements and decide which one is more like them, followed by deciding if the statement is "*sort of true*" or "*really true*" of them. The main construct Harter purports to measure in the SSSCA is social support in the form of positive regard from others (Harter, 1985b). Examples of topics assessed include the extent to which participants feel they can talk with others about their problems or feelings and the extent to which they feel accepted as they are by others. Cronbach's alpha for this scale in the present study was reported as; 0.81 for parental support, 0.94 for friend support, 0.81 for classmate support, and 0.81 for teacher support.

Child Need for Information and Support: Subscale of the Child Report of Psychosocial Care Scale

This subscale measures CWE's need for information and support relating to their epilepsy (Austin, Dunn, Huster, & Rose, 1998). Six items relate to information about their epilepsy, medications, cause of seizures, how to manage seizures, activities that they can do and keeping

safe. Six items relate to need for support in relation to talking to someone about their feelings about having epilepsy, about how to tell friends about their condition, talking about fears and concerns, the future, and handling seizures at school. CWE answer each of the 12 questions with a "*yes"* or "*no*" response. This scale has previously demonstrated good validity and internal consistency reliability (Austin et al., 1998). The coefficient alpha uncovered in the present study for this scale was 0.83.

Child Information Received: Subscale of the Child Report of Psychosocial Care Scale

This subscale measures CWE's perceived satisfaction with the level of information they have received from healthcare professionals about their epilepsy (Austin et al., 1998). There are six items to which children respond on 3-point scale ranging from "*less than I wanted*" to "*more than I wanted*". This scale has previously demonstrated good validity and internal consistency reliability (Austin et al., 1998). The coefficient alpha uncovered in the present study for this scale was 0.69.

CWE-Reported Demographic and Clinical Variables

Two demographic variables were gathered from the CWE sample; CWE age and CWE gender. Three clinical variables were gathered from the CWE sample relating to their epilepsy characteristics; seizure type, seizure visibility and seizure frequency.

7.4.2 Parent Questionnaire Materials

The materials for inclusion in the parent questionnaire are described below. These are divided into three categories: 1) parent-child communication variables, 2) psychosocial variables, and 3) demographic and clinical variables.

Parent-Reported Parent-Child Communication Variables

Parent-Child Communication about Epilepsy Questionnaire – Parent Version

The parent version of the Parent-Child Communication about Epilepsy Questionnaire consists of 38 items across six subcategories measuring parent perspectives on various aspects of parent-child communication about epilepsy; context of parent-child communication about epilepsy (8 items), content of parent-child communication about epilepsy (9 items), parents' reasons for communicating about epilepsy with CWE (6 items), parents' reasons against communicating about epilepsy with CWE (3 items), barriers and enablers of parent-child communication about

epilepsy (7 items), and parents' emotions following parent-child communication about epilepsy (5 items).

Parent-Child Communication Level

The "Parent-Child Communication Level" variable was designed by the researcher to capture the perceived level of dialogue about epilepsy between parent(s) and CWE from a parent perspective. This question incorporated the scoring key; 1 = Not at all, 2 = A little, 3 = Somewhat, and 4 = Very Much. Higher scores indicate that parents engage in a greater level of communication with CWE.

Parenting Styles and Dimensions Questionnaire (PSDQ)

The PSDQ is a validated 62-item questionnaire with a 5-point response scale; ranging from "*never*" to "*always*" (Robinson, Mandleco, Olsen, & Hart, 1995). Factors measured include; authoritativeness (27 items), authoritarianism (20 items) and permissiveness (15 items).

Authoritativeness in parenting is recognized as the most democratic of parenting styles. Parents employing an authoritative parenting style establish rules and guidelines that their children are expected to follow, however, they are responsive to their children and willing to listen to questions. When children fail to meet the expectations, these parents are nurturing and forgiving rather than punishing. They are assertive, but not intrusive and restrictive. Their disciplinary methods are largely supportive rather than punitive. Parents adopting an authoritative style seek for their children to be assertive and self-regulated as well as socially responsible. The "Authoritative Style" variable was used to capture the level of authoritative parenting that parents considered they engaged in. This authoritative style score was calculated from the total of 27 items in the PSDQ measure found in the parent questionnaire. These items were derived from the following four factors; Warmth and Involvement (11 items), Reasoning/Induction (7 items), Democratic Participation (5 items), and Good Natured/Easy Going (4 items). Parents were asked to rate statements pertaining to expressions of affection, rational guidance, and encouragement of independence, according to the scoring key; 1 = Never, 2 = Once in a While, 3 = About Half of the Time, 4 = Very Often, and 5 = Always. Higher scores indicate a greater affinity to an authoritative parenting style.

An authoritarian style is the strictest style of parenting. Parents who employ an authoritarian parenting style expect their children to follow the stringent rules. Failure to follow such rules usually results in punishment. Authoritarian parents fail to explain the reasoning behind rules.

Authoritarian parents have high demands but, unlike authoritative parents, are not responsive to their children. These parents are obedience-oriented and expect their orders to be obeyed without explanation. The "Authoritarian Style" variable was used to capture the level of authoritarian parenting that parents considered they engaged in. This authoritarian style score was calculated from the total of 20 items in the PSDQ measure found in the parent questionnaire. These items were derived from the following four factors; Verbal Hostility (4 items), Corporal Punishment (6 items), Non-reasoning, Punitive Strategies (6 items), and Directiveness (4 items). Parents were asked to rate statements pertaining to authoritarian control, parental supervision, and control by anxiety induction, according to the scoring key; 1 = Never, 2 = Once in a While, 3 = About Half of the Time, 4 = Very Often, and 5 = Always. Higher scores indicate a greater affinity to an authoritarian parenting style.

Permissive parents demand very little of their children. Parents adopting a permissive style of parenting rarely discipline their children and have relatively low expectations of maturity/self-regulation. Permissive parents are much more responsive than they are demanding. They tend to be lenient and allow considerable self-regulation thus avoiding confrontation. Permissive parents often take the role of a friend more than that of a parent to their children. The "Permissive Style" variable was used to capture the level of permissive parenting that parents considered they engaged in. This permissive style score was calculated from the total of 15 items in the PSDQ measure found in the parent questionnaire. These items were derived from the following three factors; Lack of Follow Through (6 items), Ignoring Misbehaviour (4 items), and Self-confidence (5 items). Parents were asked to rate statements pertaining to permissiveness, according to the scoring key; 1 = Never, 2 = Once in a While, 3 = About Half of the Time, 4 = Very Often, and 5 = Always. Higher scores indicate a greater affinity to a permissive parenting style.

This measure has previously demonstrated good validity and reliability (Robinson et al., 1995) with an internal consistency of; 0.89 (authoritativeness), 0.82 (authoritarianism) and 0.76 (permissiveness) in the present study.

Parent-Reported Psychosocial Variables

Parent Stigma Scale (PSS)

The PSS is a 5-item scale that measures perceived stigma in parents of CWE (Austin et al., 2004). Items included in this scale relate to how parents perceive others might view their CWE. The PSS uses a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). A higher

score reflects greater perceptions of stigma associated with their CWE having epilepsy. This scale has shown good validity and internal consistency reliability (Austin et al., 2004) with the coefficient alpha reported as 0.79 in the present study.

Parent Response to Child Illness Scale (PRCI)

The PRCI is a 35-item scale assessing parents' responses to the onset of seizures in a child (Austin et al., 2008). This scale uses a 5-point response scale; ranging from "*strongly disagree*" to "*strongly agree*". Factors measured include; child support (8 items), family life/leisure (10 items), condition management (5 items), child autonomy (6 items), and child discipline (6 items). This measure has previously shown good validity and reliability (Austin et al., 2008). The present study reports alpha coefficients for all five subscales as 0.68 (child support), 0.86 (family life\leisure), 0.54 (condition management), 0.64 (child autonomy), and 0.70 (child discipline).

Impact of Pediatric Epilepsy on the Family (IPES)

The IPES is an 11-item scale with a 5-point response scale used to specifically measure the psychosocial impact of paediatric epilepsy on the family (Camfield, Breau, & Camfield, 2001). The scale assesses the impact of epilepsy on; academic achievement, participation in activities, health, relationships with family and with peers and siblings, social activities, self-esteem and the caregiver's hopes for their child's future. This scale has previously shown good validity and reliability (Camfield et al., 2001). The co-efficient alpha for this 11 item scale was 0.91 in the present study.

Hague Restrictions in Childhood Epilepsy Scale (HARCES)

This is a 10-item scale measuring parents' perceptions of their child's disability due to restrictions their epilepsy imposes on them (Carpay et al., 1997). Higher scores are indicative of greater parent-perceived disability. This scale has demonstrated sound psychometric properties (Carpay et al., 1997) with alpha coefficient reported as 0.91 in the present study.

Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS is a 12-item scale that measures the perceived level of social support an individual experiences from 3 sources, namely; a significant other, friends, and family (Zimet, Dahlem, Zimet, & Farley, 1988). Participants respond on a scale from 1 (very strongly disagree) to 7 (very strongly agree) with higher scores indicative of greater perceived levels of social support.

This measure has shown good validity and reliability (Zimet et al., 1988). The coefficient alpha for the total scale was reported as 0.94 in the present study, with reported coefficient alphas for each of the subscales also demonstrating high internal reliability; 0.92 (significant other), 0.92 (family), and 0.95 (friends).

Parent Need for Information and Help: Subscale of the Parent Report of Psychosocial Care Scale

This 14-item subscale measures parent need for information and support related to their CWE's condition (Austin et al., 1998). Six items relate to a need for information about their CWE's epilepsy, treatment, cause of seizures, how to handle future seizures and preventing injury, and eight items relate to need for help, i.e. - handling responses of others and their child's response to seizures, discussing epilepsy-related concerns and fears. Parents respond on a scale from 1 (no need for information/support) to 3 (strong need for information/support). This measure has shown good validity and reliability (Austin et al., 1998), with a coefficient alpha of 0.91 in the present study.

Parent Information Received: Subscale of the Parent Report of Psychosocial Care Scale

This 8-item subscale measures parents' satisfaction with the perceived level of information they have received from healthcare professionals in relation to their CWE's epilepsy (Austin et al., 1998). There are eight items to which parents respond on a scale from 1 (less than I wanted) to 3 (more than I wanted). This measure has shown good validity and reliability (Austin et al., 1998), with a coefficient alpha of 0.91 in the present study.

Parent-Reported Demographic and Clinical Variables

Five demographic variables were gathered from the parent sample; parent age, parent gender, CWE age (parent-report), CWE gender (parent-report), and parent education level.

Five clinical variables were gathered from the parent sample relating to their CWE's epilepsy characteristics; seizure type, seizure visibility, seizure frequency, family history of epilepsy, and seizure severity assessed by the pre-validated Seizure Severity Scale described below.

Seizure Severity Scale (SSS)

This scale was originally developed to reflect the degree to which seizures disrupt the everyday lives of adults. This scale has been revised for completion by parents to rate the severity of their CWE's seizures (Caplin, Austin, Dunn, Shen, & Perkins, 2002; Austin et al., 2004). This revised

scale contains nine items. Items assess the level of intrusiveness, disruptiveness, and effects of seizures rated from 0 (never) to 3 (always). Other items measure time of disruption, seizure length, and time until resuming normal activities. This measure has shown good validity and reliability previously (Wagner, Smith, Ferguson, & Wannamaker, 2009) with a coefficient alpha of 0.79 demonstrated in the present study.

7.4.3 Questionnaire Piloting

A pilot of the CWE and parent questionnaires was conducted with six families. The purpose of this pilot was to ascertain the clarity of instructions, readability and ease of questionnaire completion. This pilot also aimed to determine length of time to complete questionnaires for both CWE and parents. Data gathered via this pilot study were not included in the final quantitative analysis. In two instances, the pilot was conducted in the presence of the family (CWE and parents) in order to discuss any potential issues they had. In the remaining four instances, the pilot was conducted remotely whereby families were posted a survey pack along with a feedback questionnaire and a stamped and addressed envelope for return of the questionnaires.

No major problems were reported by CWE or parents within the feedback they provided on the questionnaires. The questionnaires took approximately one hour to complete for both CWE and parents. A small number of minor language amendments were made in order to change the American terminology in some of the pre-validated instruments to more widely used terms in Ireland. For example, the term "seizure condition" was replaced with epilepsy. Aside from these minor issues, no major amendments were made to either questionnaire.

7.5 Data Analysis

Data were analysed using the statistical software package SPSS 22 (IBM Corp, 2013).

Descriptive statistics were performed in order to provide an overview of the sample's demographic and clinical characteristics. Following this, a series of correlational analyses were performed on the data arising from both parent and CWE questionnaires in order to examine the specific objectives I set out to assess within the quantitative phase of this mixed method study.

Prior to commencement of the correlational analyses, all data were tested for normality in order to ascertain whether the use of parametric or non-parametric statistical analyses were appropriate. All data obtaining a skewness or kurtosis statistic greater than +1 or less than -1

were considered to have a non-normal distribution (Bulmer, 1974) and subsequently non-parametric tests were used when examining these data. Correlational analyses on all normally distributed data were performed via Pearson's product moment correlations, whereas non-normally distributed data were analysed using Spearmen's rho analyses. All correlations are appropriately reported according to the test used in the following chapter.

I sought to examine a number of relationships between parent-child communication variables and CWE/parent demographic, clinical and psychosocial variables. The analyses were performed in the following order; 1) correlational analyses and/or t-test analyses examining solely CWE data (including parent-child communication variables, demographic and clinical characteristics, and other psychosocial variables), 2) correlational analyses and/or t-test analyses examining solely parent data (including parent-child communication variables, demographic and clinical characteristics, and other psychosocial variables), and finally 3) correlational analyses performed across CWE and parent samples examining the relationships between parent-child communication and CWE's and parents' psychosocial wellbeing. One-tailed correlational analyses were used to test previously hypothesized associations. For all other analyses, two-tailed correlational tests were used.

7.6 Conclusion

This chapter described the quantitative method employed in the second phase of this mixed methods study. The next chapter will present the quantitative findings for both CWE and parent participants.

Chapter 8: Phase Two: Quantitative Findings

8.0 Introduction

Results from the quantitative phase of this mixed-methods study will be presented throughout this chapter. The aims and hypotheses of this phase have been outlined in section 7.2 of Chapter 7. This chapter begins by providing descriptive demographic and clinical information about CWE and parent participants.

8.1 Sample Description (Demographic and Clinical Characteristics)

A total of 119 participants returned completed questionnaires. These 119 participants consisted of 72 parents and 47 CWE. The questionnaires were largely completed in hardcopy format by both parents (60 hardcopy, 12 online) and CWE (45 hardcopy, 2 online).

8.1.1 Response Rate

A total of 165 hardcopy information packs containing CWE and parent questionnaires were posted to potential participants. 45 CWE questionnaires and 60 parent questionnaires were returned. Due to a lack of information available from the Qualtrics survey platform regarding precisely how many times the online questionnaire was accessed, and the number of potentially eligible participants who accessed the questionnaire via advertisement links or other means (e.g. – word of mouth), it is not possible to comment on the response rate of the online questionnaire. Therefore, as the overall response rate is dependent on the combination of postal returns and online questionnaires completed, it is not possible to calculate an overall response rate for this phase of the study.

8.1.2 CWE Demographic and Clinical Characteristics

All CWE who completed a questionnaire (n = 47) were aged between 8 – 18 years (M = 13.19, SD = 2.82). Seizure types currently or previously experienced by participating CWE were varied. The most common seizures experienced by CWE were absence (64%) and tonic-clonic seizures (47%) and the least common was ESES (2%). CWE participants reported that the frequency of their seizures varied from; daily (6%), frequently (6%), weekly (6%), monthly (4%), occasionally (32%), yearly (11%) and seizure-free (30%), with four percent of CWE reporting their seizure frequency as "Unknown". Two thirds of CWE had experienced side effects as a result of antiepileptic medication, with remaining CWE reporting no side effects.

The CWE of parents who completed a questionnaire (n = 72) were also aged between 8 – 18 years (*M* = 13.2, *SD* = 3.02). Considering the information gathered from participating parents, seizure types currently or previously experienced by their CWE varied widely. The most common seizures experienced by CWE were absence (58%) and tonic-clonic seizures (57%) and the least common was ESES (1%). Similarly, seizure frequency of CWE participants varied from; daily (11%), frequently (6%), weekly (4%), monthly (1%), occasionally (29%), yearly (13%), and seizure-free (29%). Seven percent of parents reported their CWE's seizure frequency as "Unknown", indicating that they were unable to identify with any of the classifications provided within the questionnaire and/or accurately specify their CWE's seizure frequency at the time of questionnaire completion (e.g. – parents responded with answers such as "He had two major seizures and a few small ones"). 68% of CWE had experienced side effects as a result of antiepileptic medication, 26% had no experience of such side effects and 6% were unsure if they had experienced antiepileptic medication-related side effects. Finally, the majority of parents (57%) reported no family history of epilepsy, 30% of parents reported a family history, and 13% of parents reported being unsure about the existence of epilepsy previously within the family. A detailed breakdown of CWE demographic and clinical characteristics, as reported by both CWE (n = 47) and their parent(s) (n = 72), is provided in Table 8.1.

Table 8.1: ***CWE Demographic and Clinical Characteristics***

	Parent-Reported		**CWE-Reported**	
Child Age	**Years**		**Years**	
Mean	13.2		13.19	
SD	3.02		2.82	
Range	8 – 18		8 – 18	
Child Gender	**N**	**%**	**N**	**%**
Male	32	44	22	47
Female	35	49	25	53
Unspecified	5	7	0	0
Child Seizure Type	**N**	**%**	**N**	**%**
Absence	42	58	30	64
Tonic-Clonic	41	57	22	47
Simple Partial	16	22	8	17
Complex Partial	25	35	11	23
Myoclonic	16	22	10	21
Atonic	9	13	2	4
Tonic	10	14	4	9
Clonic	16	22	5	11
ESES	1	1	1	2
Child Seizure Frequency	**N**	**%**	**N**	**%**
Daily *(once a day or more)*	8	11	3	6
Frequently *(several times a week)*	4	6	3	6
Weekly *(about once a week)*	3	4	3	6

Child Seizure Frequency *(continued)*	**N**	**%**	**N**	**%**
Monthly *(about once a month)*	1	1	2	4
Occasionally *(less than monthly)*	21	29	15	32
Yearly *(about once a year)*	9	13	5	11
Seizure-Free	21	29	14	30
Unknown	5	7	2	4
Medication Side Effects Experienced	**N**	**%**	**N**	**%**
Yes	49	68	31	66
No	19	26	16	34
Unsure	4	6	0	0
Family History of Epilepsy	**N**	**%**		
Yes	22	30	*CWE participants were not asked about family history of epilepsy*	
No	41	57		
Unsure	9	13		

8.1.3 Parent Demographic Characteristics

The parents of 32 male CWE and 35 female CWE participated in this study. A further 5 parents of CWE participated but did not identify the gender of their child. A detailed breakdown of participating parent demographic information is provided in Table 8.2. The majority of parents who returned completed questionnaires were female (92%), within the 41 – 55 years age bracket (75%), and had tertiary level education (62%). All parents were the biological mother or father to the CWE in question.

Table 8.2: ***Parent Demographic Characteristics***

Parent Age	**N**	**%**
25 years or under	1	1.5
26 – 40 years	13	18
41 – 55 years	54	75
56 years or older	3	4
Unspecified	1	1.5
Parent Gender	**N**	**%**
Male	6	8
Female	66	92
Parent Education Level	**N**	**%**
Less than Junior Certificate	2	3
Junior Certificate	7	10
Leaving Certificate	17	24
Higher Certificate	19	26
Ordinary Bachelor Degree	5	7
Honours Bachelor Degree	7	10
Higher Diploma	7	10
Master's Degree	6	8
Doctoral Degree	1	1
Unspecified	1	1

8.1.4 Parent-CWE Dyad Demographic Characteristics

For every completed CWE questionnaire there was a linked parent questionnaire, meaning that data from 47 parent-child dyads were gathered. Of these 47 questionnaire dyads, 42 (89%) were undertaken by mothers and 5 (11%) were undertaken by fathers. The majorities of these parents were within the 41 – 55 years age bracket (75%) and had tertiary level education (63%).

8.2 Parent-Child Communication about Epilepsy Questionnaire

8.2.1 CWE Perspectives

In this section, descriptive data will be presented on the context and content of, reasons for and against, barriers and facilitators of, and emotions following parent-child communication about epilepsy – from CWE perspectives.

Context of parent-child communication about epilepsy - CWE perspectives

Considering the context surrounding parent-child communication about epilepsy, when CWE were asked when they usually talked to their parent(s) about epilepsy the three main situational contexts chosen as really true for CWE were; before and/or following a recent hospital appointment (60%), following a seizure (59.1%), and during times in which medication present a difficulty (54.5%). In contrast, the three main situational contexts that CWE reported as not at all true to them were; when CWE are in need of support (42.2%), when CWE cannot partake in an activity due to their epilepsy (40%), and when they are worried and/or upset (33.3%). See Table 8.3 for a breakdown of this data.

Table 8.3: ***Context of parent-child communication about epilepsy – CWE Perspectives***

I usually talk to my Mum or Dad about epilepsy when…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my Mum or Dad about epilepsy
I have a seizure	44	59.1%	31.8%	6.8%	2.3%
I take my medication	45	40%	40%	20%	0%
My medication is causing me difficulties	44	54.5%	22.7%	22.7%	0%
I have a question about epilepsy	45	51.1%	44.4%	4.4%	0%
I have a hospital appointment coming up or have recently had a hospital appointment	45	60%	35.6%	4.4%	0%
I cannot take part in an activity because of my epilepsy	45	33.3%	26.7%	40%	0%
I am worried/upset	45	40%	26.7%	33.3%	0%
I need support	45	35.6%	22.2%	42.2%	0%

Content of parent-child communication about epilepsy - CWE perspectives

When asked what epilepsy-related topics CWE generally talk to their parent(s) about, the three topics of epilepsy-related conversation that CWE were likely to converse about included; CWE's antiepileptic medication (53.3%), what happens when CWE have a seizure (53.3%), and CWE's hospital appointments (51.1%). The three topics of epilepsy-related conversations which CWE largely identified as not at all true to their discussions were; things CWE cannot take part in due to their epilepsy (37.8%), their level of seizure control (37.8%), and any side effects experienced as a result of their antiepileptic medication (31.1%). See Table 8.4 for a breakdown of this data.

Table 8.4: ***Content of parent-child communication about epilepsy – CWE Perspectives***

When I talk to my Mum or Dad about epilepsy, we talk about…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my Mum or Dad about epilepsy
What epilepsy is	45	33.3%	42.2%	24.4%	0%
How I feel about having epilepsy	45	33.3%	44.4%	22.2%	0%
What happens when I have a seizure (e.g. – what I look like)	45	53.3%	33.3%	13.3%	0%
My medication	45	53.3%	42.2%	4.4%	0%
Medication side effects	45	44.4%	24.4%	31.1%	0%
My hospital appointments	45	51.1%	48.9%	0%	0%
Things I cannot take part in because of my epilepsy	45	33.3%	28.9%	37.8%	0%
Whether my seizures are controlled or not	45	40%	22.2%	37.8%	0%
Whether I will grow out of my epilepsy	45	48.9%	33.3%	17.8%	0%

Reasons for parent-child communication about epilepsy – CWE Perspectives

The three most frequently selected reasons for engaging in parent-child communication about epilepsy were; not wanting to keep secrets about their condition (44.4%), seeking to have a greater knowledge of epilepsy (35.6%), and wanting to know what to do if having a seizure (33.3%). See Table 8.5 for further information.

Table 8.5: ***Reasons for parent-child communication about epilepsy – CWE Perspectives***

I talk to my Mum or Dad about my epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my Mum or Dad about epilepsy
I don't want to feel different	45	22.2%	31.1%	46.7%	0%
I want to know what I should do if I have a seizure	45	33.3%	28.9%	37.8%	0%

I talk to my Mum or Dad about my epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my Mum or Dad about epilepsy
It helps me to deal with certain situations	45	28.9%	40%	31.1%	0%
I want to know a lot about my epilepsy	45	35.6%	37.8%	26.7%	0%
I don't want to keep secrets about my epilepsy	45	44.4%	26.7%	28.9%	0%

Reasons against parent-child communication about epilepsy – CWE Perspectives

The three most frequently identified reasons for not engaging in parent-child dialogue about epilepsy for CWE were; not wanting to worry their parent(s) (20%), avoiding participatory restrictions (15.6%), and not wanting to feel difference (13.6%). However, it must also be noted that a sizeable proportion of CWE participants responded that the following reasons were not at all true for them; parental overreaction in relation to epilepsy-related issues (60%), not wanting to feel different (56.8%), and not wanting to appear attention-seeking (56.8%). See Table 8.6 for further information.

Table 8.6: ***Reasons against parent-child communication about epilepsy – CWE Perspectives***

I don't talk to my Mum or Dad about my epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I always talk to my Mum or Dad about epilepsy
I don't want to feel different	44	13.6%	15.9%	56.8%	13.6%
I don't want to worry my Mum or Dad	45	20%	15.6%	51.1%	13.3%
I don't want my Mum or Dad to think I am looking for attention	44	11.4%	18.2%	56.8%	13.6%
If I talk to my Mum or Dad they might not let me go to things	45	15.6%	17.8%	53.3%	13.3%
My Mum or Dad will make a big deal about it	45	13.3%	13.3%	60%	13.3%

Barriers and enablers of parent-child communication about epilepsy – CWE Perspectives

When asked about what factors they consider helpful or unhelpful when engaging in a dialogue about epilepsy with their parent(s), the two factors that CWE considered most helpful when talking about epilepsy with their parents were; how much knowledge they have in relation to their epilepsy (48.9%), and how much the CWE talk to their parents about things (44.4%). However, approximately 1 in 4 CWE find that how often they have seizures (24.4%) and how they feel about epilepsy (26.7%) is not helpful when talking to their parents about epilepsy. See Table 8.7 for a breakdown of this data.

Table 8.7: ***Barriers and enablers of parent-child communication about epilepsy – CWE Perspectives***

Do any of the following things make it helpful or challenging for me to talk to my Mum or Dad about my epilepsy?	N	This helps me	This makes it difficult	This makes no difference
How much I usually talk to my Mum or Dad about things	45	44.4%	6.7%	48.9%
The amount of time that I have had epilepsy	45	35.6%	11.1%	53.3%
How much I know about my epilepsy	45	48.9%	13.3%	37.8%
How often I have seizures	45	33.3%	24.4%	42.2%
When epilepsy is on the T.V. or radio	45	37.8%	6.7%	55.6%
How I feel about my epilepsy	45	37.8%	26.7%	35.6%

Feelings following parent-child communication about epilepsy - CWE perspectives

The final aspect of parent-child communication about epilepsy that CWE were asked about was the effect of this communication on their emotions. The three feelings which CWE reported most frequently were happy (54.5%), brave (52.3%), and worry (31.8%). The majority of CWE indicated that they did not feel any embarrassment (84.1%), specialness (81.4%), or sadness (72.7%) when talking about epilepsy with their parent(s). See Table 8.8 for data breakdown.

Table 8.8: ***Feelings following parent-child communication about epilepsy – CWE Perspectives***

Talking about epilepsy with my Mum or Dad makes me feel…	N	Yes	No	Does not apply, I never talk to my Mum or Dad about my epilepsy
Happy	44	54.5%	45.5%	0%
Sad	44	27.3%	72.7%	0%
Worried	44	31.8%	68.2%	0%
Brave	44	52.3%	47.7%	0%
Embarrassed	44	15.9%	84.1%	0%
Different	44	29.5%	70.5%	0%
Special	43	18.6%	81.4%	0%

8.2.2 Parent Perspectives

In this section, descriptive data will be presented on the context and content of, reasons for and against, barriers and facilitators of, and emotions following parent-child communication about epilepsy – from parent perspectives.

Context of parent-child communication about epilepsy - Parent perspectives

Considering the context surrounding parent-child communication about epilepsy, when parents were asked when they usually talked to CWE about epilepsy the three main situational contexts chosen as particularly true to their epilepsy-related conversations were; when CWE have a question in relation to their epilepsy (76.4%), when CWE have a hospital appointment in the near future or have recently had a hospital appointment (76.1%), and when CWE need support (70.8%). In contrast, the three main situational contexts that parents reported as not at all true to them were; when CWE cannot take part in an activity due to their epilepsy (30.6%), when CWE's medication is causing difficulties (25%), and simply at times when CWE take their medication (21.4%). See Table 8.9 for data breakdown.

Table 8.9: ***Context of parent-child communication about epilepsy – Parent Perspectives***

I usually talk to my child about his/her epilepsy when…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
My child has a seizure	71	70.4%	21.1%	8.5%	0%
My child takes his/her medication	70	38.6%	40%	21.4%	0%
My child asks me questions	72	76.4%	19.4%	4.2%	0%
My child has a hospital appointment coming up or has recently had a hospital appointment	71	76.1%	19.7%	4.2%	0%
My child's medication is causing difficulties	72	58.3%	16.7%	25%	0%
My child cannot partake in an activity due to his/her epilepsy	72	44.4%	22.2%	30.6%	2.8%
My child is worried/upset	72	62.5%	27.8%	9.7%	0%
My child needs support	72	70.8%	22.2%	6.9%	0%

Content of parent-child communication about epilepsy - Parent perspectives

The three topics referred to by parents as most prominent in their epilepsy-related discussions with CWE were; CWE's antiepileptic medication (80.6%), CWE's hospital appointments (76.4%), and what epilepsy is (i.e. – explaining epilepsy to CWE) (68.1%). Conversely, the three topics which parents were least likely to discuss were; epilepsy-related restrictions that

CWE face (22.2%), CWE's medication side effects (18.1%), and the possibility of CWE growing out of their epilepsy (15.3%). See Table 8.10 for further breakdown of the data.

Table 8.10: ***Content of parent-child communication about epilepsy – Parent Perspectives***

When I talk to my child about his/her epilepsy, we talk about…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
What epilepsy is	72	68.1%	29.2%	2.8%	0%
How my child feels about having epilepsy	71	62%	35.2%	2.8%	0%
What happens when my child has a seizure (e.g. – how he/she appears)	71	67.6%	25.4%	7%	0%
My child's medication	72	80.6%	16.7%	2.8%	0%
Medication side effects	72	48.6%	33.3%	18.1%	0%
My child's hospital appointments	72	76.4%	18.1%	5.6%	0%
Restrictions my child experiences due to his/her epilepsy	72	45.8%	30.6%	22.2%	1.4%
My child's seizure control (or lack thereof)	72	58.3%	25%	15.3%	1.4%
Whether my child will grow out of his/her epilepsy	72	48.6%	34.7%	15.3%	1.4%

Reasons for parent-child communication about epilepsy - Parent perspectives

The three most frequently selected reasons for parents to engage in dialogue about epilepsy with their CWE were; to inform CWE about their epilepsy condition (88.9%), to avoid feelings of differentness for CWE (84.7%), and to help CWE deal with certain situations (79.2%). Interestingly, 11.1% of parents stated that the rationale of helping them to deal with certain situations was not at all true for them, as did 8.3% of parent respondents when asked if they spoke to CWE about epilepsy in order to not make them feel different. See Table 8.11 for data breakdown.

Table 8.11: ***Reasons for parent-child communication about epilepsy – Parent Perspectives***

I talk to my child about his/her epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
I don't want my child to feel different	72	84.7%	6.9%	8.3%	0%
I want my child to know what he/she should do in the event of a seizure	72	75%	22.2%	2.8%	0%
It helps my child to deal with certain situations	72	79.2%	16.7%	4.2%	0%
It helps me to deal with certain situations	72	65.3%	23.6%	11.1%	0%
I want my child to be informed about his/her epilepsy	72	88.9%	11.1%	0%	0%
I don't want my child to keep secrets about his/her epilepsy	72	77.8%	19.4%	2.8%	0%

Reasons against parent-child communication about epilepsy - Parent perspectives

The most frequently identified reason for parents not engaging in parent-child dialogue about epilepsy with their CWE was them not wanting CWE to dwell on their condition (31.9%). See Table 8.12 for data breakdown.

Table 8.12: ***Reasons against parent-child communication about epilepsy – Parent Perspectives***

I don't talk to my child about his/her epilepsy because…	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I always talk to my child about his/her epilepsy
I don't want to single my child out in comparison to his/her siblings	69	15.7%	12.9%	34.3%	37.1%
I don't want to worry my child	70	24.3%	14.3%	25.7%	35.7%
I don't want my child to dwell on his/her epilepsy	69	31.9%	13%	23.2%	31.9%

Barriers and enablers of parent-child communication about epilepsy - Parent perspectives

Parents were asked about the factors they consider encouraging, discouraging or non-impactful when engaging in a dialogue about epilepsy with CWE. The three factors that parents considered most encouraging when talking about epilepsy with CWE were; CWE maintaining a high level of seizure control (67.6%), parents own attitudes towards epilepsy (62%), and the level of knowledge parents had about epilepsy (60.6%). However, 19.7% of parents found that their child's disposition discouraged them from talking to their child about epilepsy. Similarly, 16.9% and 12.7% of parents reported that portrayals of epilepsy in the media and their experience of epilepsy prior to their child's diagnosis, respectively, discouraged them from talking to CWE about their epilepsy. See Table 8.13 for a breakdown of this data.

Table 8.13: ***Barriers and enablers of parent-child communication about epilepsy – Parent Perspectives***

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?	N	This encourages me	This discourages me	Not applicable, this has no impact on how much I talk to my child about his/her epilepsy
My child's disposition (i.e. – your child's temperament and nature)	71	54.9%	19.7%	25.4%
The amount of time my child has had epilepsy	70	51.4%	7.1%	41.4%
The level of information I have about my child's epilepsy	71	60.6%	11.3%	28.2%
My child's seizures are well controlled	71	67.6%	7%	25.4%
Portrayals of epilepsy in the media	71	39.4%	16.9%	43.7%

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?	N	This encourages me	This discourages me	Not applicable, this has no impact on how much I talk to my child about his/her epilepsy
My own attitudes towards epilepsy	71	62%	4.2%	33.8%
Experiences I had with epilepsy prior to my child's diagnosis	71	29.6%	12.7%	57.7%

Feelings following parent-child communication about epilepsy - Parent perspectives

The final aspect of parent-child communication about epilepsy that parents were asked about was the effect of this communication on their emotions. The two feelings which parents reported most significantly were; reassured (85.9%), and optimism (88.1%). Parents largely indicated no feelings of pessimism (91%), or discomfort/unease (89.7%). However, 32.8% of parents indicated that talking about epilepsy with CWE caused them to feel anxious. See Table 8.14 for a breakdown of this data.

Table 8.14: ***Feelings following parent-child communication about epilepsy – Parent Perspectives***

Talking about epilepsy with my child makes me feel…	N	Yes	No	Does not apply, I never talk to my child about his/her epilepsy
Reassured	71	85.9%	14.1%	0%
Optimistic	67	88.1%	11.9%	0%
Anxious	67	32.8%	67.2%	0%
Uncomfortable	68	10.3%	89.7%	0%
Pessimistic	67	9%	91%	0%

8.3 Correlational Analysis

A series of correlational analyses were performed on the data arising from CWE and parent questionnaires to establish the relationship between parent-child epilepsy-related communication and a number of demographic, clinical and psychosocial variables. The research objectives and hypotheses for this phase have been outlined earlier in section 7.2 of Chapter 7. Results uncovered from the CWE-reported data are presented first, followed by results unearthed via the parent-reported data. Descriptive information for all parent-child communication variables and psychosocial variables described in these analyses are outlined in Table 8.15.

Table 8.15: ***Descriptive Information for all CWE-reported and Parent-reported Variables***

CWE-Reported Variables					
Parent-Child Communication Variable	**N**	**Possible Range**	**Actual Range**	**Mean**	**Std. Deviation**
Mother-Child Communication Level	43	1 – 4	2 – 4	3.65	0.65
Father-Child Communication Level	43	1 – 4	1 – 4	3.37	0.93
Positive Affect of Communication	44	2 – 4	2 – 4	3.07	0.87
Negative Affect of Communication	44	4 – 8	4 – 8	5.05	1.26
Socio-Orientation	45	10 – 50	11 – 47	30.18	6.16
Concept Orientation	45	13 – 65	15 – 55	30.44	10.45
CWE Psychosocial Variable	**N**	**Possible Range**	**Actual Range**	**Mean**	**Std. Deviation**
CWE Stigma	43	8 – 40	8 – 36	17.77	8.35
CWE Illness Attitudes	38	13 – 65	24 – 59	42.37	8.91
CWE Self-Perception					
Scholastic Competence	37	6 – 24	6 – 24	14.59	4.99
Social Competence	36	6 – 24	8 – 24	17.47	4.24
Athletic Competence	37	6 – 24	7 – 24	16.62	5.11
Physical Appearance	35	6 – 24	6 – 24	16.83	5.54
Behavioural Conduct	37	6 – 24	8 – 24	16.92	4.02
Global Self-Worth	36	6 – 24	7 – 24	18.58	4.54
CWE Health-related Quality of Life					
Interpersonal Social Consequences	36	5 – 20	6 – 20	16.44	3.88
Worries and Concerns	37	5 – 20	6 – 20	13.27	3.85
Intrapersonal Emotional Issues	38	5 – 20	5 – 19	11.61	3.73
Epilepsy my Secret	39	5 – 20	7 – 20	14.95	3.82
Quest for Normality	36	5 – 20	8 – 20	16.31	3.19
CWE Perceived Social Support					
Parental Support	38	6 – 24	15 – 24	22.21	2.59
Classmate Support	38	6 – 24	11 – 24	20.74	3.28
Teacher Support	38	6 – 24	12 – 24	20.05	3.62
Close Friend Support	38	6 – 24	6 – 24	20.45	5.19
CWE Need for Info and Support					
Need for Information	41	6 – 12	6 – 12	8.66	2.01
Need for Support	40	6 – 12	6 – 12	9.68	2.12
CWE Satisfaction with Info Received	43	6 – 12	6 – 12	10.09	1.7
Parent-Reported Variables					
Parent-Child Communication Variable	**N**	**Possible Range**	**Actual Range**	**Mean**	**Std. Deviation**
Parent-Child Communication Level	70	1 – 4	2 – 4	3.51	0.68
Authoritative Style	59	27 – 135	64 – 127	102.22	12.99
Authoritarian Style	64	20 – 100	22 – 58	35.56	7.2
Permissive Style	68	15 – 75	17 – 49	31.49	6.92

Parent Psychosocial Variable	N	Possible Range	Actual Range	Mean	Std. Deviation
Parent Stigma	71	5 – 25	5 – 25	12.44	3.96
Parent Response to Child Illness					
Child Support	71	8 – 40	26 – 40	34.14	3.6
Family Life and Leisure	68	10 – 50	19 – 50	38.57	7.8
Condition Management	68	6 – 30	16 – 30	24.63	2.87
Child Autonomy	69	6 – 30	7 – 26	18.93	4.28
Child Discipline	70	5 – 25	10 – 24	18.69	3.52
Perceived Impact of Epilepsy on Family	66	0 – 33	0 – 27	10.03	7.69
Perceived Impact of Epilepsy on CWE	68	10 – 40	10 – 36	18.84	7.7
Parent Perceived Social Support					
Significant Other Support	72	4 – 28	12 – 28	23.24	3.89
Family Support	71	4 – 28	4 – 28	21.92	5.32
Friends Support	71	4 – 28	7 – 28	21.72	4.51
Parent Need for Info and Help					
Need for Information	68	6 – 18	6 – 18	9.21	3.02
Need for Help	68	8 – 24	8 – 22	13.35	3.97
Parent Satisfaction with Info Received	66	8 – 16	8 – 16	13.58	2.77

8.3.1 Parent-Child Communication and Demographic Variables: CWE-Reported

A series of analyses were performed between CWE-reported parent-child communication variables (including level of epilepsy-related communication with mother, level of epilepsy-related communication with father, positive affect of epilepsy-related communication, negative affect of epilepsy-related communication, the perceived level of socio-orientation, and the perceived level of concept-orientation within families communication patterns) and CWE-reported demographic variables, including; age and gender. Pearson's product moment and Spearman's rho correlations were performed between CWE parent-child communication variables and CWE-reported age. Two-tailed correlations were used in order to investigate any relationships between variables. Subsequently, independent samples t-tests and Mann Whitney U tests were performed between CWE parent-child communication variables and CWE-reported gender.

The level of positive affect perceived by CWE following epilepsy-related communication was significantly negatively correlated with their age, $r(42)= -.32$, $p < .05$ (two-tailed), indicating that CWE were less likely to experience positive affect of parent-child communication about epilepsy as they got older. No further statistically significant relationships were identified. The results of these analyses are displayed in Table 8.16.

Table 8.16: ***Analysis of Parent-Child Communication and Demographic Variables: CWE-Reported***

Demographic Variable	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed
CWE Age	.108 *(r)*	.491	.086 *(r)*	.582	-.319 *(p)*	.035*	.124 *(r)*	.422	-.159 *(p)*	.296	.274 *(p)*	.069
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Demographic Variable	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed
CWE Gender	*U* = 193	.282	*U* = 199	.429	*t* = .218	.828	*U* = 218	.59	*t* = -.268	.79	*t* = .060	.952
					df = 42				df = 43		df = 43	

8.3.2 Parent-Child Communication and Clinical Variables: CWE-Reported

A series of analyses were performed between CWE-reported parent-child communication variables and CWE-reported clinical variables, including; seizure type, seizure visibility (if CWE had experienced seizures in the company of those other than the nuclear family), and seizure frequency. Independent samples t-tests and Mann Whitney U tests were performed between CWE parent-child communication variables and CWE-reported seizure type and seizure visibility. Pearson's product moment and Spearman's rho correlations were performed between CWE parent-child communication variables and CWE-reported seizure frequency. Two-tailed correlations were used in order to investigate any existing relationships between variables.

A significant effect for seizure type was recorded with CWE experiencing tonic clonic seizures indicating that they talked to their mother about epilepsy more frequently than CWE not experiencing tonic-clonic seizures, $U = 114$, $p < .05$. Additionally, greater perceived negative affect following parent child communication was recorded in CWE experiencing tonic seizures [$U = 29$, $p < .05$] than CWE not experiencing this seizure type. No further statistically significant relationships were identified. The results of these analyses are displayed in Table 8.17.

Table 8.17: ***Analysis of Parent-Child Communication and Clinical Variables: CWE-Reported***

Clinical Variable	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	t or U	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed
Seizure Type:												
Tonic-Clonic	*U* = 114	.001*	*U* = 163	.167	*t* = .363	.719	*U* = 181	.291	*t* = .782	.438	*t* = -.633	.53
					df = 40				df = 41		df = 41	
Absence	*U* = 154	.195	*U* = 156	.402	*t* = -.122	.903	*U* =177	.594	*t* = -.213	.832	*t* = -.616	.541
					df = 40				df = 41		df = 41	
Simple Partial	*U* = 111	.841	*U* = 115	.956	*U* = 119	1.000	*U* = 113	.771	*U* = 120	.853	*U* = 93	.287
Complex Partial	*U* = 118	.345	*U* = 113	.151	*U* = 115	.280	*U* = 98	.095	*U* = 109	.188	*U* = 153	.994
Myoclonic	*U* = 110	.316	*U* = 101	.247	*U* = 130	.657	*U* = 129	.517	*U* = 140	.707	*U* = 145	.820
Atonic	*U* = 15	1.000	*U* = 24	.524	*U* = 15	.280	*U* = 24	.429	*U* = 39	.893	*U* = 33	.666
Tonic	*U* = 42	.564	*U* = 44	.231	*U* = 61	.568	*U* = 29	.021*	*U* = 72	.814	*U* = 77	.974
Clonic	*U* = 42	.564	*U* = 44	.231	*U* =74	1.000	*U* = 38	.088	*U* = 78	1.000	*U* = 67	.663
ESES	*U* = 15	1.000	*U* = 4	.195	*U* = 20	1.000	*U* = 2	.095	*U* = 13	.721	*U* = 15	.744
Seizure Visibility	*U* = 84	.904	*U* = 79	.772	*U* = 72	.219	*U* = 101	.94	*U* = 69	.19	*U* = 92	.633
Clinical Variable	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**
	(p or r)	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**
Seizure frequency	-.099 *(r)*	.537	-.063 *(r)*	.696	-.177 *(p)*	.262	-.239 *(r)*	.127	.002 *(p)*	.991	-.088 *(p)*	.577
	n = 41		n = 41		n = 42		n = 42		n = 43		n = 43	

8.3.3 Parent-Child Communication and Psychosocial Variables: CWE-Reported

Pearson's product moment and Spearman's rho correlations were conducted between CWE parent-child communication variables and CWE-reported psychosocial variables, including; CWE perceived stigma, CWE's attitudes towards their illness, CWE's self-perception, CWE's health-related quality of life, CWE's perceived level of social support, CWE's need for epilepsy-related information and support, and their satisfaction with the level of epilepsy-related information they have received. One-tailed correlations were performed in order to assess the existence of previously hypothesized relationships between variables. The results of these correlational analyses are outlined below according to the numbered hypotheses detailed in chapter seven. The results of these analyses are displayed in Table 8.18.

In the following analyses, open communication strategies in CWE were characterised by a greater level of epilepsy-related parent-child communication, CWE experiencing a greater perceived positive affect experienced following parent-child communication, and CWE reporting less perceived socio-orientation, whereas closed communication strategies in CWE were characterised by a lower level of epilepsy related parent-child communication, CWE experiencing a greater perceived negative affect following parent-child communication, and CWE reporting less perceived concept-orientation.

Table 8.18: ***Analysis of Parent-Child Communication and Psychosocial Variables: CWE-Reported***

Psychosocial Variable	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed
CWE Stigma	-.116 *(r)*	.238	-.167 *(r)*	.152	-.155 *(p)*	.163	.642 *(r)*	.000**	-.205 *(p)*	.094	.189 *(p)*	.112
	n = 40		n = 40		n = 42		n = 42		n = 43		n = 43	
CWE Attitude towards Epilepsy	-.183 *(r)*	.143	-.170 *(r)*	.157	.043 *(p)*	.400	-.679 *(r)*	.000**	.320 *(p)*	.025*	-.282 *(p)*	.043*
	n = 36		n = 37		n = 37		n = 37		n = 38		n = 38	
CWE Self-Perception												
Scholastic Competence	.007 *(r)*	.484	.092 *(r)*	.299	-.150 *(p)*	.191	-.278 *(r)*	.050	.207 *(p)*	.110	-.111 *(p)*	.257
	n = 34		n = 35		n = 36		n = 36		n = 37		n = 37	
Social Competence	-.127 *(r)*	.237	-.125 *(r)*	.237	.007 *(p)*	.485	-.520 *(r)*	.001**	.394 *(p)*	.009**	-.209 *(p)*	.111
	n = 34		n = 35		n = 35		n = 35		n = 36		n = 36	
Athletic Competence	-.035 *(r)*	.422	.045 *(r)*	.400	-.197 *(p)*	.125	.150 *(r)*	.191	.050 *(p)*	.385	.113 *(p)*	.253
	n = 34		n = 35		n = 36		n = 36		n = 37		n = 37	
Physical Appearance	-.211 *(r)*	.119	-.323 *(r)*	.031*	-.025 *(p)*	.443	-.172 *(r)*	.165	.285 *(p)*	.048*	-.297 *(p)*	.041*
	n = 33		n = 34		n = 34		n = 34		n = 35		n = 35	
Behavioural Conduct	.105 *(r)*	.277	.096 *(r)*	.292	.070 *(p)*	.342	-.341 *(r)*	.021*	.346 *(p)*	.018*	-.523 *(p)*	.000**
	n = 34		n = 35		n = 36		n = 36		n = 37		n = 37	
Global Self-Worth	.020 *(r)*	.454	.061 *(r)*	.364	-.018 *(p)*	.458	-.497 *(r)*	.001**	.413 *(p)*	.006**	-.423 *(p)*	.005
	n = 34		n = 35		n = 35		n = 35		n = 36		n = 36	
CWE Heath-related Quality of Life												
Interpersonal Social Consequences	.226 *(r)*	.099	.177 *(r)*	.158	-.067 *(r)*	.351	-.563 *(r)*	.000**	.160 *(r)*	.175	-.318 *(r)*	.029*
	n = 34		n = 34		n = 35		n = 35		n = 36		n = 36	
Worries and Concerns	-.119 *(r)*	.251	.032 *(r)*	.427	-.140 *(p)*	.208	-.198 *(r)*	.123	.093 *(p)*	.293	-.062 *(p)*	.358
	n = 34		n = 35		n = 36		n = 36		n = 37		n = 37	
Intrapersonal Emotional Issues	.107 *(r)*	.271	.238 *(r)*	.085	.043 *(p)*	.400	-.436 *(r)*	.003**	.309 *(p)*	.030*	-.210 *(p)*	.103
	n = 35		n = 35		n = 37		n = 37		n = 38		n = 38	

	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	Correlation Coefficient (p or r)	Sig. 1-tailed	Correlation Coefficient (p or r)	Sig. 1-tailed	Correlation Coefficient (p or r)	Sig. 1-tailed	Correlation Coefficient (p or r)	Sig. 1-tailed	Correlation Coefficient (p or r)	Sig. 1-tailed	Correlation Coefficient (p or r)	Sig. 1-tailed
Epilepsy my Secret	.252 *(r)*	.069	.303 *(r)*	.036*	.198 *(p)*	.117	-.531 *(r)*	.000**	.300 *(p)*	.032*	-.285 *(p)*	.039*
	n = 36		n = 36		n = 38		n = 38		n = 39		n = 39	
Quest for Normality	-.009 *(r)*	.481	.058 *(r)*	.375	-.281 *(p)*	.051	-.597 *(r)*	.000**	.336 *(p)*	.022*	-.052 *(p)*	.382
	n = 33		n = 33		n = 35		n = 35		n = 36		n = 36	
CWE Perceived Social Support												
Parental Support	.232 *(r)*	.087	.234 *(r)*	.084	.092 *(r)*	.293	-.346 *(r)*	.018*	.068 *(r)*	.343	-.643 *(r)*	.000**
	n = 36		n = 36		n = 37		n = 37		n = 38		n = 38	
Classmate Support	.110 *(r)*	.266	.071 *(r)*	.342	.052 *(r)*	.380	-.403 *(r)*	.007**	.292 *(r)*	.038*	-.406 *(r)*	.006**
	n = 35		n = 35		n = 37		n = 37		n = 38		n = 38	
Teacher Support	.216 *(r)*	.103	.087 *(r)*	.308	.358 *(p)*	.015*	-.287 *(r)*	.043*	.158 *(p)*	.171	-.611 *(p)*	.000**
	n = 36		n = 36		n = 37		n = 37		n = 38		n = 38	
Close Friend Support	.164 *(r)*	.170	.033 *(r)*	.424	-.099 *(r)*	.280	-.224 *(r)*	.091	.079 *(r)*	.319	-.262 *(r)*	.056
	n = 36		n = 36		n = 37		n = 37		n = 38		n = 38	
CWE Information and Support Needs												
Need for Information	-.086 *(r)*	.304	.023 *(r)*	.445	-.200 *(p)*	.108	-.241 *(r)*	.067	.187 *(p)*	.121	.123 *(p)*	.222
	n = 38		n = 38		n = 40		n = 40		n = 41		n = 41	
Need for Support	-.005 *(r)*	.489	.044 *(r)*	.399	-.030 *(p)*	.428	-.317 *(r)*	.025*	.150 *(p)*	.177	-.144 *(p)*	.188
	n = 37		n = 37		n = 39		n = 39		n = 40		n = 40	
CWE Satisfaction with Info Received	-.032 *(r)*	.422	.057 *(r)*	.363	.210 *(p)*	.091	-.245 *(r)*	.059	.159 *(p)*	.154	-.086 *(p)*	.293
	n = 40		n = 40		n = 42		n = 42		n = 43		n = 43	

Hypothesis 1(Perceived Stigma)

It was hypothesized that open communication strategies in CWE will be associated with lower levels of perceived epilepsy-related stigma amongst CWE, whereas closed communication strategies in CWE will be associated with higher levels of perceived epilepsy-related stigma amongst CWE.

CWE negative affect following epilepsy-related communication was significantly positively correlated with stigma perceptions amongst CWE, $\rho(40)=.64$, $p < .001$ (one-tailed), indicating that CWE who experienced more negative feelings following talking about epilepsy were likely to have higher stigma perceptions relating to their condition.

Hypothesis 2 (Illness Attitudes)

It was hypothesized that open communication strategies in CWE will be associated with positive illness attitudes amongst CWE, whereas closed communication strategies in CWE will be associated with negative illness attitudes amongst CWE.

A significant negative correlation was observed between CWE's negative affect of epilepsy-related communication and their attitude towards their illness, $\rho(35)= -.68$, $p < .001$ (one-tailed), with CWE who reported more negative feelings following epilepsy-related communication reporting more negative attitudes towards their epilepsy. A significant positive correlation existed between CWE perceiving less socio orientation within their family (i.e. – less closed communication) and their attitudes towards they epilepsy, signifying that CWE in families were less closed communication occurred held more positive epilepsy-related attitudes, $r(36)= .32$, $p < .05$ (one tailed). Similarly, a significant negative correlation existed between CWE perceiving less concept orientation within their family (i.e. – less open communication) and their attitudes towards their epilepsy, with CWE in families where less open communication occurred holding more negative illness attitudes, $r(36)= -.28$, $p < .05$ (one-tailed).

Hypothesis 3 (Self-Perception)

It was hypothesized that open communication strategies in CWE will be associated with higher CWE self-esteem across six self-perception domains; scholastic competence, social competence, athletic competence, physical appearance, behavioural conduct and global self-worth, whereas closed communication strategies in CWE will be associated with lower CWE self-esteem across these six self-perception domains.

The level of epilepsy-related communication CWE engaged in with fathers was significantly negatively correlated with their perceived physical appearance, $\rho(32)= -.32$, $p < .05$ (one-tailed) (i.e. – CWE who talked about their epilepsy with their fathers less were less likely to have positive perceptions of their physical appearance).

Significant negative correlations were observed between CWE's level of negative affect following epilepsy-related communication and the domains of social competence ($\rho(33)= -.52$, $p < .001$ [one-tailed]), behavioural conduct ($\rho(34)= -.34$, $p < .05$ [one-tailed]), and global self-worth ($\rho(33)= -.50$, $p < .001$ [one-tailed]), indicating that CWE who experienced more negative feelings following epilepsy-related discussions also held more negative perceptions of themselves in terms of how they interacted socially, how they behaved, and their overall self-adequacy/self-worth.

A significant positive correlation existed between CWE perceiving less socio-orientation within their family (i.e. – less closed communication) and their perceived social competence ($r(34)= .39$, $p < .01$ [one-tailed]), physical appearance ($r(33)= .29$, $p < .05$ [one-tailed]), behavioural conduct ($r(35)= .35$, $p < .05$ [one-tailed]), and global self-worth ($r(34)= .41$, $p < .01$ [one-tailed]), with CWE in families with less closed communication surrounding epilepsy reporting greater confidence in knowing how to make friends/understanding what it takes to be popular, their physical appearance, how they behaved, and their overall self-adequacy/self-worth. Finally, less concept orientation within families (i.e. – less open communication) was significantly negatively correlated with CWE's perceptions of their own physical appearance ($r(33)= -.30$, $p < .05$ [one-tailed]), and how they well they behave ($r(35)= -.52$, $p < .001$ [one tailed]), indicating that CWE within families with less open communication strategies were likely to have a more negative self-perception of their appearance and behaviour.

Hypothesis 4 (Health-related Quality of Life)

It was hypothesized that open communication strategies in CWE will be associated with a greater CWE perceived health-related quality of life (HRQoL) across five domains; interpersonal/social consequences of epilepsy, worries and concerns relating to epilepsy, intrapersonal emotional issues experienced as a result of epilepsy, the degree to which CWE wished to keep epilepsy a secret, and the desire for a sense of normality experienced by CWE with epilepsy, whereas closed communication strategies in CWE will be associated with lower CWE perceived health-related quality of life across these five domains.

The level of epilepsy-related communication CWE engaged in with fathers was significantly positively correlated with HRQoL in the Epilepsy my Secret domain, with CWE who reported a greater level of CWE-father epilepsy-related communication also reporting a greater felt necessity to keep their condition a secret, $\rho(34)= .30$, $p < .05$ (one-tailed).

CWE who reported experiencing a greater level of negative affect following epilepsy-related discussions reported significantly poorer HRQoL across the four following domains; Interpersonal/Social Consequences ($\rho(33)= -.56$, $p < .001$ [one-tailed]), Intrapersonal Emotional Issues ($\rho(35)= -.44$, $p < .01$ [one-tailed]), Epilepsy my Secret ($\rho(36)= -.53$, $p < .001$ [one-tailed]), and Quest for Normality ($\rho(33)= -.60$, $p < .001$ [one-tailed]), demonstrating that CWE who experienced negative feelings as a result of talking about epilepsy with their parents also reported; a greater number of social consequences relating to epilepsy, experiencing a greater level of emotional issues, a desire to conceal their epilepsy from others, and a greater need for normality abounding their diagnosis.

Finally, less perceived socio-orientation (i.e. – less closed communication) within families communication patterns was significantly positively correlated with CWE's intrapersonal emotional issues ($r(36)= .31$, $p<.05$ [one-tailed]), desire for secrecy surrounding epilepsy ($r(37)= .30$, $p < .05$ [one-tailed]), and quest for normalcy ($r(34)= .34$, $p < .05$ [one-tailed]), whereas less perceived concept orientation (i.e. – less open communication) was significantly negatively correlated with poorer HRQoL for CWE across the Interpersonal/Social Consequences and Epilepsy my Secret domains ($\rho(34)= -.32$, $p < .05$ [one-tailed], and $r(37)= -.29$, $p < .05$ [one-tailed], respectively). Thus, indicating that CWE within families who facilitated less closed communication surrounding epilepsy reported less intrapersonal emotional issues relating to epilepsy, less desire for secrecy, and less need for normality surrounding their condition; whereas CWE within families incorporating less open communication strategies reported incurring a greater level of interpersonal and social consequences due to epilepsy, and held a greater desire for secrecy surrounding their diagnosis.

Hypothesis 5 (Perceived Social Support)

It was hypothesized that open communication strategies in CWE will be associated with higher levels of social support, particularly from parental figures, whereas closed communication strategies in CWE will be associated with lower levels of social support, particularly from parental figures.

CWE who reported experiencing a greater level of positive affect (positive feelings surrounding epilepsy-related communication) reported significantly higher levels of perceived support from teachers, $r(35)= .36$, $p < .05$ (one-tailed). Conversely, levels of negative affect experienced by CWE were negatively linked to perceived levels of support from parents ($\rho(35)= -.35$, $p < .05$ [one-tailed]), classmates, ($\rho(35)= -.40$, $p < .001$ [one-tailed]), and teachers ($\rho(35)= -.29$, $p < .05$ [one-tailed]), indicating that CWE who felt more negative feelings following epilepsy-related familial discussions perceived less social support from these groups.

Considering the relationship between family communication patterns and CWE's perceived social support, less perceived socio-orientation (i.e. – less closed communication) within families communication patterns was significantly positively correlated with classmate support ($\rho(36)= .29$, $p < .05$ [one-tailed]), whereas less perceived concept orientation (i.e. – less open communication) within families communication patterns was significantly correlated with lesser perceived social support from parents ($\rho(36)= -.64$, $p < .001$ [one-tailed], classmates ($\rho(36)= -.41$, $p < .01$ [one-tailed]), and teachers ($r(36)= -.61$, $p < .001$ [one-tailed]). Thus, indicating that CWE within families who facilitated less closed communication surrounding epilepsy reported greater perceived support from classmates; whereas CWE within families incorporating less open communication strategies reported lesser perceived social support from parents, classmates and teachers.

Hypothesis 6 (Need for Information and Support)

It was hypothesized that open communication strategies in CWE will be associated with a lesser need for information and support relating to their epilepsy, whereas closed communication strategies in CWE will be associated with a greater need for information and support relating to their epilepsy.

Considering CWE's reported need for epilepsy-related support; CWE negative affect was significantly negatively correlated with their need for support, indicating that CWE who reported more negative feelings following epilepsy-related familial discussions reported less need for support, $\rho(37)= -.32$, $p < .05$ (one-tailed).

Hypothesis 7 (Satisfaction with Level of Information Received)

It was hypothesized that open communication strategies in CWE will be associated with greater satisfaction with the level of information they have received relating to their epilepsy, whereas closed communication strategies in CWE will be associated with less satisfaction with the level

of information they have received relating to their epilepsy. No significant support of this hypothesis was found.

8.3.4 Parent-Child Communication and Demographic Variables: Parent-Reported

A series of analyses were performed between parent-reported parent-child communication variables (i.e. level of epilepsy-related communication with their CWE and perceived parenting style; authoritative, authoritarian, and permissive) and parent-reported demographic variables, including; CWE age, CWE gender, parent age, parent gender, and parent education level. Pearson's product moment and Spearman's rho correlations were performed between parent-child communication variables and parent-reported; CWE age, parent age, and parent education level. Two-tailed correlations were used in order to investigate any existing relationships between variables. Subsequently, independent samples t-tests and Mann Whitney U tests were performed between parent-child communication variables and parent-reported; CWE gender and parent gender.

A significant effect for parent gender was recorded with fathers of CWE significantly more likely to adopt a permissive parenting style compared to mothers of CWE, $U = 93$, $p < .05$. Additionally, this style of parenting was negatively correlated with parent education level ($r(65) = -.33$, $p < .01$ [two-tailed]), indicating that parents with a lower education level were more likely to parent in a permissive style. Finally, an authoritarian parenting style (typically associated with low prioritisation of parent-child communication) was significantly negatively associated with CWE's age ($r(59) = -.26$, $p < .05$ [two-tailed]), indicating that parents were less likely to parent in an authoritarian manner and engage in closed communication as CWE got older. The results of these analyses are displayed in Table 8.19.

Table 8.19: ***Analysis of Parent-Child Communication and Demographic Variables: Parent-Reported***

Demographic Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed
CWE Age	.222 *(r)*	.071	-.088 *(p)*	.52	-.263 *(p)*	.041*	.075 *(p)*	.552
	n = 67		n = 56		n = 61		n = 65	
Parent Age	-.109 *(r)*	.373	-.225 *(p)*	.076	.111 *(p)*	.388	.160 *(p)*	.196
	n = 69		n = 58		n = 63		n = 67	
Parent Education Lvl	-.110 *(r)*	.369	.067 *(p)*	.618	-.099 *(p)*	.438	-.330 *(p)*	.006**
	n = 69		n = 58		n = 64		n = 67	
Demographic Variable	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed
CWE Gender	*U* = 518	.915	*t* = -.22	.827	*t* = -1.004	.319	*t* = -.239	.812
			df = 53		df = 59		df = 61	
Parent Gender	*U* = 152	.806	*U* = 150	.876	*U* = 117	.209	*U* = 93	.045*

8.3.5 Parent-Child Communication and Clinical Variables: Parent-Reported

A series of analyses were performed between parent-reported parent-child communication variables and parent-reported clinical variables, including; seizure type, seizure visibility (if CWE had experienced seizures in the company of those other than the nuclear family), seizure frequency, seizure severity, and if a family history of epilepsy was known. Independent samples t-tests and Mann Whitney U tests were performed between parent-child communication variables and parent-reported seizure type, seizure visibility, and if a family history of epilepsy was known. Pearson's product moment and Spearman's rho correlations were performed between parent-child communication variables and parent-reported seizure frequency, and seizure severity. Two-tailed correlations were used in order to investigate any existing relationships between variables.

A significant effect for seizure type was recorded. Parents of CWE experiencing absence seizures adopted a more authoritative parenting style (i.e. – the most democratic parenting style, valuing open parent-child communication) ($t(57) = 2.443$, $p < .05$) than parents of CWE who did not experience absence seizures. Parents of CWE experiencing simple partial seizures adopted a more permissive parenting style (i.e. – a style that is obedience-oriented and typically associated with lower prioritization of parent-child communication) ($U = 276$, $p < .05$) than parents of CWE who did not experience simple partial seizures. Additionally, an authoritarian parenting style was significantly negatively correlated with seizure severity ($r(49) = -.30$, $p < .05$ [two-tailed]), indicating that parents of CWE with less severe seizures endorsed a more authoritarian parenting style. The results of these analyses are displayed in Table 8.20.

Table 8.20: ***Analysis of Parent-Child Communication and Clinical Variables: Parent-Reported***

Clinical Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	t or U	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed	*t or U*	Sig. 2-tailed
Seizure Type:								
Tonic-Clonic	*U* = 560	.598	*t* = -.318	.752	*t* = -.614	.542	*t* = -.244	.808
			df = 57		df = 62		df = 66	
Absence	*U* = 532	.399	*t* = 2.443	.018*	*t* = .022	.983	*t* = -1.787	.078
			df = 57		df = 62		df = 66	
Simple Partial	*U* = 354	.375	*U* = 272	.45	*U* = 325	.911	*U* =276	.042*
Complex Partial	*U* = 513	.508	*t* = -.709	.481	*t* = .825	.413	*t* = .251	.802
			df = 57		df = 62		df = 66	
Myoclonic	*U* = 414	.787	*U* = 236	.101	*U* = 259	.084	*U* = 394	.755
Atonic	*U* = 212	.198	*U* = 185	.402	*U* = 197	.332	*U* = 248	.752
Tonic	*U* = 291	.875	*U* = 176	.545	*U* = 227	.693	*U* = 209	.309
Clonic	*U* = 324	.102	*U* = 222	.26	*U* = 278	.156	*U* = 321	.172
ESES	*U* = 21	1.000	*U* = 5	.203	*U* = 10	.359	*U* = 9	.294
Seizure Visibility	*U* = 392	1.000	*U* = 114	.263	*U* = 247	.436	*U* = 275	.328
Family history of epilepsy	*U* = 409	.502	*U* = 224	.197	*U* = 298	.445	*U* = 341	.532
Clinical Variable	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**	**Correlation Coefficient**	**Sig.**
	(p or r)	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**	***(p or r)***	**2-tailed**
Seizure frequency	-.100 *(r)*	.427	.088 *(p)*	.518	.129 *(p)*	.331	.233 *(p)*	.066
	n = 65		n = 56		n = 59		n = 63	

Clinical Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.
	(p or r)	2-tailed	*(p or r)*	2-tailed	*(p or r)*	2-tailed	*(p or r)*	2-tailed
Seizure severity	.151 *(r)*	.274	-.011 *(p)*	.943	-.304 *(p)*	.030*	-.007 *(p)*	.960
	n = 54		n = 47		n = 51		n = 53	

8.3.6 Parent-Child Communication and Psychosocial Variables: Parent Reported

Pearson's product moment and Spearman's rho correlations were conducted between parent-child communication variables and parent-reported psychosocial variables, including; parents' perceived stigma, parents' response to their child's illness, parents' perceived impact of epilepsy (on both the family and their child with epilepsy), parents' perceived level of social support, parents' need for epilepsy-related information and support, and their satisfaction with the level of epilepsy-related information they have received. One-tailed correlations were performed in order to assess the existence of previously hypothesized relationships between variables. The results of these analyses are displayed in Table 8.21.

In the following analyses, open communication strategies in parents were characterised by a greater level of epilepsy-related parent-child communication and parents reporting the adoption of an authoritative parenting style, whereas closed communication strategies in parents were characterised by a lower level of epilepsy related parent-child communication and parents reporting the adoption of an authoritarian or permissive parenting style.

Table 8.21: ***Analysis of Parent-Child Communication and Psychosocial Variables: Parent-Reported***

Psychosocial Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed	Correlation Coefficient *(p or r)*	Sig. 1-tailed
Parent Stigma	-.132 *(r)*	.139	-.116 *(p)*	.191	.283 *(p)*	.012*	.153 *(p)*	.106
	n = 69		n = 59		n = 64		n = 68	
Parent Response to CWE Illness	.193 *(r)*	.065	.303 *(p)*	.012*	-.335 *(p)*	.004**	-.398 *(p)*	.001**
	n = 63		n = 55		n = 61		n = 62	
Child Support	.131 *(r)*	.142	.529 *(p)*	.000**	-.272 *(p)*	.015*	-.310 *(p)*	.005**
	n = 69		n = 59		n = 64		n = 68	
Family Life and Leisure	.095 *(r)*	.223	.114 *(p)*	.199	-.126 *(p)*	.161	-.255 *(p)*	.020*
	n = 66		n = 57		n = 64		n = 65	
Condition Management	.235 *(r)*	.029*	.454 *(p)*	.000**	-.129 *(p)*	.161	-.156 *(p)*	.109
	n = 66		n = 57		n = 61		n = 64	
Child Autonomy	.221 *(r)*	.035*	-.075 *(p)*	.289	-.157 *(p)*	.107	-.220 *(p)*	.038*
	n = 68		n = 58		n = 64		n = 66	
Child Discipline	-.148 *(r)*	.117	.188 *(p)*	.079	-.481 *(p)*	.000**	-.466 *(p)*	.000**
	n = 67		n = 58		n = 64		n = 67	
Perceived Impact of Epilepsy on Family	.076 *(r)*	.275	-.186 *(p)*	.084	.063 *(p)*	.319	.119 *(p)*	.179
	n = 64		n = 56		n = 59		n = 62	
Perceived Impact of Epilepsy on CWE	.122 *(r)*	.165	-.083 *(p)*	.266	-.086 *(p)*	.252	-.012 *(p)*	.463
	n = 66		n = 59		n = 62		n = 66	
Parent Perceived Social Support	.053 *(r)*	.332	.099 *(p)*	.227	-.021 *(p)*	.434	-.280 *(p)*	.010*
	n = 69		n = 59		n = 64		n = 68	
Significant Other Support	.027 *(r)*	.412	.173 *(p)*	.095	.058 *(p)*	.324	-.133 *(p)*	.140
	n = 70		n = 59		n = 64		n = 68	
Family Support	.098 *(r)*	.212	.094 *(r)*	.240	-.126 *(r)*	.160	-.263 *(r)*	.015*
	n = 69		n = 59		n = 64		n = 68	
Friends Support	.032 *(r)*	.399	.219 *(r)*	.048*	-.077 *(r)*	.273	-.351 *(r)*	.002**
	n = 69		n = 59		n = 64		n = 68	

Psychosocial Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.	Correlation Coefficient	Sig.
	(p or r)	1-tailed	*(p or r)*	1-tailed	*(p or r)*	1-tailed	*(p or r)*	1-tailed
Parent Information and Support Needs								
Need for Information	.086 *(r)*	.247	-.207 *(r)*	.060	.128 *(r)*	.160	.119 *(r)*	.173
	n = 66		n = 58		n = 62		n = 65	
Need for Support	-.044 *(r)*	.362	-.240 *(p)*	.035*	.131 *(p)*	.152	.113 *(p)*	.182
	n = 66		n = 58		n = 63		n = 66	
Parent Satisfaction with Info Received	-.111 *(r)*	.190	-.098 *(p)*	.233	-.114 *(p)*	.190	-.057 *(p)*	.326
	n = 64		n = 57		n = 61		n = 64	

Hypothesis 8 (Perceived Stigma)

It was hypothesized that open communication strategies in parents will be associated with lower levels of perceived epilepsy-related stigma, whereas closed communication strategies in parents will be associated with higher levels of perceived epilepsy-related stigma amongst parents.

Parents who reported higher levels of perceived epilepsy-related stigma endorsed a more authoritarian parenting style (i.e. – a style that is obedience-oriented and typically associated with lower prioritization of family communication), $r(62)= .28$, $p<.05$ (one-tailed).

Hypothesis 9 (Response to Child Illness)

It was hypothesized that open communication strategies in parents will be associated with positive perceptions/responses to the CWE's condition, whereas closed communication strategies in parents will be associated with negative perceptions/responses to this child's condition. Parent response to their child's illness was measured overall and additionally across five subscales, namely; Child Support, Family Life and Leisure, Condition Management, Child Autonomy, and Child Discipline.

A more positive parent response to CWE illness overall was significantly positively correlated with an authoritative parenting style (i.e. – the most democratic parenting style, valuing open family communication) ($r(53)= .30$, $p <.05$ [one-tailed]. Conversely, parent response to child illness was significantly negatively correlated with both authoritarian ($r(59)= -.34$, $p <.01$ [one-tailed]) and permissive ($r(59)= -.40$, $p <.01$ [one-tailed]) parenting styles, both typically favouring more closed family communication strategies in their approach.

Considering the "Child Support" subscale, as hypothesized, higher scores were significantly positively associated with an authoritative parenting style ($r(57)= .53$, $p<.001$ [one-tailed]), yet significantly negatively correlated with both authoritarian ($r(62)= -.27$, $p <.05$ [one-tailed]) and permissive ($r(66)= -.31$, $p <.01$ [one-tailed]) parenting styles. Thus indicating that parents who provided greater emotional support to CWE in relation to their epilepsy were more likely to endorse more open family communication (utilising an authoritative parenting style) than closed family communication (incorporating either an authoritarian or permissive style of parenting). Less participation in family leisure activities (as measured by the Family Life and Leisure subscale) was associated with parents adopting a permissive parenting style, $r(63)= -.26$, $p <.05$ (one-tailed). Higher scores on the Condition Management subscale (measuring parents' confidence in their ability to effectively manage their child's condition) were significantly

positively linked with a greater level of family communication about epilepsy ($\rho(64)= .24$, $p<.05$ [one-tailed]) and an authoritative parenting style (typically endorsing open communication; $r(55)= .45$, $p <.001$ [one-tailed]). Greater parental encouragement of CWE's autonomy/independence was significantly positively correlated with a greater level of family epilepsy-related communication ($\rho(66)= .22$, $p <.05$ [one-tailed]), but negatively associated with a permissive parenting style ($r(64)= -.22$, $p <.05$ [one-tailed]). Finally, a significant negative correlation was observed between parental confidence in their ability to manage CWE's behaviour (as measured by the Child Discipline subscale) and authoritarian ($r(62)= -.48$, $p<.001$ [one-tailed]) and permissive ($r(65)= -.47$, $p<.001$ [one-tailed]) parenting styles, both typically favouring more closed family communication strategies.

Hypothesis 10 (Perceived Impact of Epilepsy on Family)

Parents' perceived impact of CWE's epilepsy was measured across two areas; (1) Parents' perceived impact of epilepsy on the nuclear family (as measured by the Impact of Pediatric Epilepsy on the Family Scale [IPES]), and (2) Parents perceived impact of epilepsy on the CWE themselves (as measured by the Hague Restrictions in Childhood Epilepsy Scale [HARCES]).

It was hypothesized that open communication strategies in parents will be associated with parents perceiving a lesser impact of epilepsy on the family, whereas closed communication strategies in parents will be associated with parents perceiving a greater impact of epilepsy on the family. However, no statistically significant relationships were uncovered between parent-child communication about epilepsy (as perceived by parents) and their reported perceived level impact of epilepsy on the family.

Hypothesis 11 (Perceived Impact of Epilepsy on CWE)

It was also hypothesized that open communication strategies in parents will be associated with parents perceiving a lesser impact of epilepsy on CWE themselves, whereas closed communication strategies in parents will be associated with parents perceiving a greater impact of epilepsy on CWE. Similarly, no statistically significant relationships were uncovered between family communication about epilepsy (as perceived by parents) and their reported perceived level impact of epilepsy on CWE.

Hypothesis 12 (Perceived Social Support)

It was hypothesized that open communication strategies in parents will be associated with higher levels of parent perceived social support, whereas closed communication strategies in parents

will be associated with lower levels of parent perceived social support. Parents perceived social support was measured as an overall construct and across three subscales; significant other support, family support, and friends support.

Lower levels of perceived social support by parents overall were significantly associated with the adoption of a permissive parenting style (one in which parents often take the role of a friend more than that of a parent to CWE, and family communication is largely undervalued), $r(66) = -.28$, $p < 0.5$ (one-tailed). Similarly, lower perceived levels of family support were also linked to permissive parenting styles, $\rho(66) = -.26$, $p < .05$ (one-tailed). Finally, parents who reported high levels of support from friends were likely to endorse a more open authoritative parenting style ($\rho(57) = .22$, $p < .05$ [one-tailed]), whereas those reporting low level friend support were likely to endorse a more closed permissive parenting style ($\rho(66) = -.35$, $p < .01$ [one-tailed]).

Hypothesis 13 (Need for Information and Support)

It was hypothesized that open communication strategies in parents will be associated with parents expressing a low need for information and support, whereas closed communication strategies in parents will be associated with parents expressing a high need for information and support in relation to CWE's epilepsy. However, no statistically significant relationships were uncovered between parent-child communication about epilepsy (as perceived by parents) and their need for epilepsy-related information.

Considering parents' reported need for epilepsy-related support; parent need for epilepsy-related support was significantly negatively correlated with the adoption of an authoritative parenting style, indicating that parents in need of a greater level of epilepsy-related support were less likely to adopt an authoritative parenting style within the home, and thus less likely to engage in open communication, $r(56) = -.24$, $p < .05$ (one-tailed).

Hypothesis 14 (Satisfaction with Level of Information Received)

It was hypothesized that open communication strategies in parents will be associated with greater satisfaction with the level of information they have obtained relating to their CWE's epilepsy, whereas closed communication strategies in parents will be associated with less satisfaction with the level of information they have obtained relating to their CWE's epilepsy. However, no statistically significant relationships were uncovered between family communication about epilepsy (as perceived by parents) and parental satisfaction with the epilepsy-related information they have received.

8.3.7 Relationships between Parent-Child Communication and Parent and Child Psychosocial Variables

In order to investigate any existing relationships between parent-child communication and CWE and parent psychosocial variables, a series of correlational analyses were conducted. These analyses are described below in the following order; (1) correlational analyses examining links between CWE-reported parent-child communication variables and parent psychosocial variables, and (2) correlational analyses examining associations between parent-reported parent-child communication variables and CWE psychosocial variables. As no pre-determined hypotheses have been applied, two-tailed correlations were used in order to investigate any existing relationships between variables.

Parent-Child Communication (CWE-Reported) and Parent Psychosocial Variables

Correlational analyses were performed in order to investigate any links between CWE parent-child communication variables and parent psychosocial variables. The results of these analyses are displayed in Table 8.22.

Table 8.22: ***Analysis of Parent-Child Communication (CWE-Reported) and Parent Psychosocial Variables***

Psychosocial Variable	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed
Parent Stigma	-.144 *(r)*	.356	-.096 *(r)*	.538	.056 *(p)*	.717	.040 *(r)*	.798	-.220 *(p)*	.146	.097 *(p)*	.527
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Parent Response to CWE Illness	.170 *(r)*	.300	.059 *(r)*	.719	.406 *(p)*	.776	-.225 *(r)*	.157	.265 *(p)*	.089	-.093 *(p)*	.559
	n = 39		n = 40		n = 41		n = 41		n = 42		n = 42	
Child Support	.113 *(r)*	.472	-.125 *(r)*	.424	.250 *(p)*	.102	-.066 *(r)*	.669	.254 *(p)*	.092	-.194 *(p)*	.201
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Family Life and Leisure	.061 *(r)*	.704	.039 *(r)*	.807	.071 *(r)*	.653	-.290 *(r)*	.062	.054 *(r)*	.732	-.056 *(r)*	.72
	n = 41		n = 42		n = 42		n = 42		n = 43		n = 43	
Condition Management	.376 *(r)*	.017*	.283 *(r)*	.077	.186 *(p)*	.239	.126 *(r)*	.428	.265 *(p)*	.086	-.306 *(p)*	.046*
	n = 40		n = 40		n = 42		n = 42		n = 43		n = 43	
Child Autonomy	.204 *(r)*	.195	.164 *(r)*	.300	-.022 *(p)*	.888	-.405 *(r)*	.007**	.050 *(p)*	.749	.016 *(p)*	.917
	n = 42		n = 42		n = 43		n = 43		n = 44		n = 44	
Child Discipline	.171 *(r)*	.273	-.004 *(r)*	.981	-.031 *(p)*	.842	-.083 *(r)*	.592	.225 *(p)*	.137	-.072 *(p)*	.638
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Perceived Impact of Epilepsy on Family	.071 *(r)*	.673	.045 *(r)*	.790	.203 *(p)*	.216	.359 *(r)*	.025*	-.206 *(p)*	.203	.039 *(p)*	.811
	n = 38		n = 38		n = 39		n = 39		n = 40		n = 40	
Perceived Impact of Epilepsy on CWE	.023 *(r)*	.886	-.064 *(r)*	.692	.006 *(r)*	.969	.376 *(r)*	.014*	-.087 *(r)*	.577	.281 *(r)*	.068
	n = 41		n = 41		n = 42		n = 42		n = 43		n = 43	
Parent Perceived Social Support	.257 *(r)*	.096	.116 *(r)*	.459	-.275 *(p)*	.071	-.211 *(r)*	.169	.279 *(p)*	.064	.009 *(p)*	.951
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Significant Other Support	.113 *(r)*	.470	.065 *(r)*	.678	-.331 *(p)*	.028*	-.062 *(r)*	.691	.279 *(p)*	.063	.024 *(p)*	.877
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Family Support	.224 *(r)*	.149	.164 *(r)*	.293	-.092 *(r)*	.551	-.213 *(r)*	.164	.226 *(r)*	.136	-.017 *(r)*	.911
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	
Friends Support	.274 *(r)*	.076	-.007 *(r)*	.966	-.286 *(p)*	.060	-.155 *(r)*	.314	.272 *(p)*	.071	.001 *(p)*	.992
	n = 43		n = 43		n = 44		n = 44		n = 45		n = 45	

Psychosocial Variable	Mother-Child Communication Lvl		Father-Child Communication Lvl		Perceived Positive Affect		Perceived Negative Affect		Socio-Orientation		Concept-Orientation	
	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed
Parent Information and Support Needs												
Need for Information	.192 *(r)*	.230	.047 *(r)*	.770	-.030 *(p)*	.851	.164 *(r)*	.300	-.301 *(p)*	.050*	.172 *(p)*	.27
	n = 41		n = 41		n = 42		n = 42		n = 43		n = 43	
Need for Support	.013 *(r)*	.936	-.140 *(r)*	.376	-.049 *(p)*	.756	.522 *(r)*	.000**	-.342 *(p)*	.025	.126 *(p)*	.421
	n = 42		n = 42		n = 42		n = 42		n = 43		n = 43	
Satisfaction with Info Received	-.002 *(r)*	.991	.162 *(r)*	.317	-.022 *(p)*	.892	-.275 *(r)*	.086	.102 *(p)*	.525	.068 *(p)*	.671
	n = 41		n = 40		n = 40		n = 40		n = 41		n = 41	

A significant positive correlation was observed between parental confidence in condition management and CWE perceived level of epilepsy-related communication with their mother, $\rho(38)= .38$, $p< .05$ (two-tailed), indicating that parents who were more confident in managing their child's epilepsy engaged in a greater level of epilepsy-related communication with CWE. Conversely, a lower level of parental confidence in managing their child's epilepsy was associated with CWE perceiving less concept orientation within their family's communication pattern (i.e. – CWE perceived less open communication within the family), $r(41)= -.31$, $p< .05$ (two-tailed). Finally, less parental encouragement for CWE autonomy was significantly correlated with CWE experiencing more negative feelings following epilepsy-related familial discussions, $\rho(41)= -.41$, $p<.01$ (two-tailed).

Greater CWE negative affect following epilepsy-related communication with parents was associated with parents perceiving a greater impact of epilepsy on the family, $\rho(37)= .36$, $p< .05$ (two-tailed). Similarly, greater CWE negative affect following epilepsy-related communication with parents was associated with parents perceiving a greater impact of epilepsy on CWE, $\rho(40)= .38$, $p< .05$ (two-tailed). Greater CWE positive affect following epilepsy-related communication with parents was associated with parents perceiving low levels of support from their significant other, $r(42)= -.33$, $p< .05$ (two-tailed).

Considering the relationship between CWE's perceived communication and parent need for epilepsy-related information/ support; a significant negative correlation existed between CWE perceiving less socio orientation within their family (i.e. – less closed communication) and their parents need for information, signifying that parents of CWE in families where less closed communication occurred had less need for epilepsy-related information, $r(41)= -.30$, $p <.05$ (two tailed). Also, a greater parental need for support in relation to their child's epilepsy was significantly correlated with CWE experiencing negative affect (negative feelings following epilepsy-related discussions within the family), $\rho(40)= .52$, $p< .001$ (two-tailed).

No further statistically significant relationships were demonstrated between CWE-reported parent-child communication variables and the following parent psychosocial variables; perceived stigma, need for epilepsy-related information, and satisfaction with epilepsy-related information received.

Parent-Child Communication (Parent-Reported) and CWE Psychosocial Variables

The series of correlational analyses conducted to investigate any existing associations between parent reported parent-child communication variables and CWE psychosocial variables are detailed in this section. The results of these analyses are displayed in Table 8.23.

Table 8.23: ***Analysis of Parent-Child Communication (Parent-Reported) and CWE Psychosocial Variables***

Psychosocial Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed	Correlation Coefficient *(p or r)*	Sig. 2-tailed
CWE Stigma	.152 *(r)*	.343	-.151 *(p)*	.381	.201 *(p)*	.219	.191 *(p)*	.232
	n = 41		n = 36		n = 39		n = 41	
CWE Attitude towards Epilepsy	-.293 *(r)*	.083	.481 *(p)*	.005**	-.203 *(p)*	.241	-.231 *(p)*	.176
	n = 36		n = 32		n = 35		n = 36	
CWE Self-Perception								
Scholastic Competence	-.207 *(r)*	.226	-.001 *(p)*	.996	.193 *(p)*	.274	-.003 *(p)*	.987
	n = 36		n = 31		n = 34		n = 35	
Social Competence	.147 *(r)*	.398	.167 *(p)*	.386	-.106 *(p)*	.557	-.068 *(p)*	.701
	n = 35		n = 29		n = 33		n = 34	
Athletic Competence	.142 *(r)*	.408	-.137 *(p)*	.472	.259 *(p)*	.139	-.040 *(p)*	.820
	n = 36		n = 30		n = 34		n = 35	
Physical Appearance	-.121 *(r)*	.497	-.023 *(p)*	.905	.019 *(p)*	.918	.013 *(p)*	.941
	n = 34		n = 29		n = 32		n = 34	
Behavioural Conduct	-.019 *(r)*	.911	.172 *(p)*	.363	-.323 *(p)*	.062	-.091 *(p)*	.605
	n = 36		n = 30		n = 34		n = 35	
Global Self-Worth	-.140 *(r)*	.423	.175 *(p)*	.355	.089 *(p)*	.621	-.106 *(p)*	.546
	n = 35		n = 30		n = 33		n = 35	
CWE Heath-related Quality of Life								
Interpersonal Social Consequences	-.100 *(r)*	.567	.200 *(r)*	.290	-.074 *(r)*	.685	-.128 *(r)*	.470
	n = 35		n = 30		n = 32		n = 34	
Worries and Concerns	-.156 *(r)*	.364	.165 *(p)*	.385	.339 *(p)*	.050*	.052 *(p)*	.765
	n = 36		n = 30		n = 34		n = 35	
Intrapersonal Emotional Issues	-.156 *(r)*	.356	.031 *(p)*	.869	-.112 *(p)*	.529	-.020 *(p)*	.910
	n = 37		n = 31		n = 34		n = 36	
Epilepsy my Secret	-.138 *(r)*	.407	-.045 *(p)*	.807	-.209 *(p)*	.228	-.080 *(p)*	.638
	n = 38		n = 32		n = 35		n = 37	

Psychosocial Variable	Parent-Child Communication Level		Authoritative Parenting Style		Authoritarian Parenting Style		Permissive Parenting Style	
	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed	Correlation Coefficient (*p or r*)	Sig. 2-tailed
Quest for Normality	-.132 *(r)*	.450	.058 *(p)*	.763	.064 *(p)*	.724	-.115 *(p)*	.518
	n = 35		n = 30		n = 33		n = 34	
CWE Perceived Social Support								
Parental Support	-.021 *(r)*	.902	.199 *(r)*	.284	.028 *(r)*	.875	.039 *(r)*	.823
	n = 37		n = 31		n = 34		n = 36	
Classmate Support	.033 *(r)*	.848	.243 *(r)*	.181	-.176 *(r)*	.320	.085 *(r)*	.618
	n = 37		n = 32		n = 34		n = 37	
Teacher Support	-.089 *(r)*	.600	-.001 *(p)*	.997	.204 *(p)*	.248	.153 *(p)*	.373
	n = 37		n = 31		n = 34		n = 36	
Close Friend Support	.044 *(r)*	.798	.300 *(r)*	.101	-.125 *(r)*	.480	-.147 *(r)*	.392
	n = 37		n = 31		n = 34		n = 36	
CWE Information and Support Needs								
Need for Information	-.258 *(r)*	.112	.129 *(p)*	.468	-.139 *(p)*	.411	.051 *(p)*	.757
	n = 39		n = 34		n = 37		n = 39	
Need for Support	-.184 *(r)*	.268	.209 *(p)*	.236	-.192 *(p)*	.261	-.075 *(p)*	.656
	n = 38		n = 34		n = 36		n = 38	
CWE Satisfaction with Info Received	.192 *(r)*	.228	.054 *(p)*	.756	-.302 *(p)*	.062	-.002 *(p)*	.991
	n = 41		n = 36		n = 39		n = 41	

A significant positive correlation was observed between an authoritative parenting style and CWE's attitude towards their condition, $r(30) = .48$, $p < .01$ (two-tailed), indicating that an authoritative parenting style (incorporating more open communication within their approach) was associated with more positive CWE attitudes towards epilepsy. A significant positive correlation was also observed between an authoritarian parenting style and CWE's worries and concerns in relation to their epilepsy, $r(32) = .34$, $p < .05$ (two-tailed), indicating that authoritarian parenting style (incorporating more closed communication and strictness within their approach to parenting) was associated with a higher level of CWE epilepsy-related worry and concern.

No further statistically significant relationships were demonstrated between parent-reported parent-child communication variables and the following CWE psychosocial variables; perceived stigma, self-perception, perceived social-support, need for epilepsy-related information and support, and satisfaction with epilepsy-related information received.

8.4 Summary of the Quantitative Findings

Throughout the present chapter, descriptive findings relating to the context and content of, reasons for and against, barriers and facilitators of, and emotions following parent-child communication about epilepsy, for both CWE and their parents, have been outlined. Additionally, relationships between parent-child dialogue about epilepsy and a number demographic, clinical, and psychosocial variables have been explicated.

Key information has been elucidated from the newly designed Parent-Child Communication about Epilepsy Questionnaire. Considering CWE perspectives on communicating about epilepsy with their parent(s), CWE generally spoke to their parent(s) about their condition before and/or following hospital appointments and/or seizures, and during times of medication-related difficulties. Similarly CWE reported that conversations with parent(s) generally centered on their medication, what happens when they have a seizure, and their hospital appointments. The primary reasons for CWE engaging in parent-child communication about epilepsy was to not keep secrets about their epilepsy, and also to obtain a greater knowledge of their condition. However, 1 in 5 CWE stated that they would not talk to their parent(s) about epilepsy for fear of causing parental worry. Almost half of the CWE sample stated that they found their level of knowledge they had surrounding their epilepsy to be helpful when discussing the condition with their parent(s), however, 1 in 4 CWE find how often they have seizures, and how they feel about epilepsy, to be unhelpful. Finally, a majority of CWE reported feeling happy and brave

following epilepsy-related conversations; with just under one third of CWE reporting feelings of worry following epilepsy-related communication.

Considering parents' perspectives on communicating about epilepsy with CWE, parents generally relayed talking to CWE about epilepsy when they had epilepsy-related questions, around the time of hospital appointments, and when they felt CWE were in need of support. Discussions relating to medication, hospital appointments, and explanations of epilepsy were at the forefront of the majority of parents' epilepsy-related conversations with CWE. Parents frequently reported engaging in a dialogue about epilepsy with CWE to inform them about their epilepsy, to avoid feelings of differentness for CWE, and to help them to deal with certain situations. However, almost 1 in 3 parents reported not talking to CWE about epilepsy to discourage them from dwelling on their condition. Parents considered a high level of seizure control, their own attitudes towards epilepsy, and the level of knowledge they had about epilepsy to be encouraging factors in talking about epilepsy with CWE. Despite this, a barrier to talking about epilepsy with CWE for almost 1 in 5 parents was their child's disposition. The majority of parents reported feeling reassured and optimistic following epilepsy-related discussions; however, 1 in 3 parents indicated that talking about epilepsy with CWE caused them anxiety.

To create a comprehensive summation of the findings uncovered via the correlational analyses conducted, a concise account of what each parent-child communication variable was significantly correlated with is presented below.

Considering the *level of epilepsy-related communication* CWE engaged in with their parents, a higher level of communication with mothers (as reported by CWE) was significantly positively correlated with greater parental confidence in managing their child's condition and significantly negatively correlated with CWE experiencing tonic-clonic seizures. A higher level of epilepsy-related communication with fathers (as reported by CWE) was significantly associated with CWE's desire to keep epilepsy a secret and CWE possessing less confidence in their physical appearance.

Greater *positive affect of epilepsy-related communication* (i.e. – positive feelings experienced by CWE following epilepsy-related discussions within the family context) was significantly correlated with CWE being older in age, CWE perceiving a greater level of social support from teachers, and their parents perceiving less social support from their significant other.

Greater *negative affect of epilepsy-related communication* (i.e. – negative feelings experienced by CWE following epilepsy-related discussions within the family context) was significantly correlated with the following factors for CWE; higher stigma perceptions amongst, poorer attitudes towards their condition, poorer perceived social competence, poorer perceived behavioural conduct, a lowered sense of self-worth, greater perceived level of epilepsy-related social consequences, a greater perceived level of emotional issues relating to epilepsy, a greater desire to conceal their epilepsy, a greater felt need for normality surrounding their epilepsy, lower perceived social support from parents, teachers and classmates, and a greater need for epilepsy-related support. Additionally, greater negative affect of epilepsy-related communication was associated with less parental encouragement of CWE's autonomy, parents' perceiving a greater impact of epilepsy on both the family and their child, and a greater parental need for epilepsy-related support.

With regard to the *level of socio-orientation and concept-orientation*, CWE perceiving less socio-orientation (i.e. – less closed communication and more open communication) was significantly associated with; positive illness attitudes, greater perceived social competence, greater confidence in physical appearance, greater perceived behavioural conduct, a greater sense of self-worth, fewer intrapersonal emotional issues due to epilepsy, less desire for secrecy surrounding epilepsy, less felt need for normality surrounding their epilepsy, and greater classmate support. CWE perceiving more open family communication was also related to parents reporting less need for epilepsy-related information. Conversely, CWE perceiving less concept orientation within their family (i.e. – less open communication and more closed communication) was significantly associated with; possessing a more negative attitude towards their condition, less confidence in physical appearance, less perceived behavioural conduct, perceiving a greater level of epilepsy-related social consequences, greater desire for secrecy surrounding epilepsy, and less support from parents, teachers and classmates. CWE perceiving more closed family communication was also related to less parental confidence in managing their child's condition.

A higher *level of epilepsy-related communication* with their CWE (as reported by parents) was significantly associated with; greater confidence in managing their child's condition and greater encouragement of their child's independence.

Considering parenting styles, *an authoritative parenting style* (i.e. – a style in which parents value open family communication) was significantly correlated with; a more positive response to their child's illness overall, providing their child with greater support relating to their

condition, greater confidence in managing their child's condition, greater perceived level of support from friends, and less need for epilepsy-related support. An authoritative parenting style was also significantly associated with more positive CWE attitudes towards their illness. Finally, an authoritative parenting style was significantly negatively associated with parents of CWE experiencing absence seizures.

An *authoritarian parenting style* (i.e. – a style that is obedience-oriented and typically associated with lower prioritization of family communication) was significantly correlated with; greater stigma perceptions amongst parents, a more negative response to their child's illness overall, less provision of condition-related support for their child, and less confidence in managing their child's behaviour. An authoritarian parenting style was also significantly associated with CWE's age (with parents were less likely to parent in an authoritarian manner as CWE got older), and CWE's seizure severity (with parents of CWE with less severe seizures endorsing an authoritarian approach). Finally, an authoritarian parenting style was associated with a greater level of epilepsy-related worries/ concerns for CWE.

A *permissive parenting style* (i.e. – a style in which parents often take the role of a friend more than that of a parent to CWE and family communication is often overlooked) was significantly correlated with; parent gender, parents of CWE experiencing simple partial seizures, a more negative response to their child's illness overall, less provision of condition-related support for their child, less family participation in leisure activities, less affordance of autonomy to their child, less confidence in managing their child's behaviour, lower perceived levels of social support overall and, more specifically, lower perceived social support from family and friends. Finally, a permissive parenting style was significantly negatively correlated with parents' education level.

These quantitative findings will be discussed in further detail in the following chapter according to the results of analyses from the CWE sample, the parent sample, and analyses conducted across both CWE and parents.

Chapter 9: Phase Two: Quantitative Discussion

9.0 Introduction

In this chapter, the quantitative findings will be critically discussed. This discussion will focus on the descriptive findings uncovered via the parent-child communication about epilepsy questionnaire. The associations uncovered between CWE-reported communication variables and other (demographic, clinical, and psychosocial) variables will be discussed, followed by the associations uncovered between parent-reported communication variables and other (demographic, clinical, and psychosocial) variables. Finally, the strengths and limitations of this second phase will be outlined.

9.1 CWE and Parent Perspectives of Epilepsy-related Communication

9.1.1 Context of Epilepsy-related Communication

The main situational contexts in which CWE talked about epilepsy with their parent(s) were; before or following epilepsy-related hospital/clinic appointments, when they had a seizure, and when their antiepileptic medication was causing difficulties. However, over 1 in 3 CWE did not seek to communicate about epilepsy with their parents in times when they were worried or needing support.

A common thread underlying the situational contexts in which CWE discuss epilepsy with parents is the occurrence of visible epilepsy-related events (such as seizures or hospital appointments). The visibility of chronic illnesses has been previously associated with greater stigmatisation and condition-concealment (Joachim & Acorn, 2000a), poorer body-image (Waskul & Vannini, 2012), and disclosure difficulties (Vickers, 1997). The present study presents pioneering evidence of the difficulties that condition invisibility presents for parent-child communication about the condition, that is CWE are less like to engage in parent-child dialogue about epilepsy when the condition is deemed to be invisible. Waskul and Vannini (2012) argue that when a condition becomes invisible, its reappearance can shock the sufferer; in this case, CWE. Parent-child communication can serve as a source of coping and understanding for the child (Jackson, Bijstra, Oostra, & Bosma, 1998). Given the potential for epilepsy to reappear in the form of unpredictable seizures, it is imperative that CWE are emotionally prepared for this possibility. The present findings, however, suggest that CWE tend not to discuss epilepsy during periods of invisibility. This finding has implications for the

potential importance of epilepsy-related conversation even when CWE are not experiencing epilepsy-related events.

The most common contexts in which parents talked about epilepsy with CWE were; before or following epilepsy-related hospital/clinic appointments, and when CWE experienced seizures.

Considering differences between CWE's and parents' perspectives of the contexts in which they talk about epilepsy together, 42% of CWE indicated that they did not seek to talk about epilepsy with their parents when they were in need of support. Conversely, the majority of parents stated that they engaged in epilepsy-related dialogue with CWE at times which they deemed CWE to be in need of greater support. Previous research has documented that approximately 1 in 5 CWE feel insufficiently supported by family members (Hirfanoglu et al., 2009). These findings may indicate a lack of agreement in when CWE are deemed in need of emotional support.

Furthermore, over half of CWE participants indicated that they spoke to parents about epilepsy during times in which antiepileptic medication posed a difficulty in their lives, however 1 in 4 parents stated that this context was not one in which they discussed epilepsy with CWE. Paediatric chronic illness medication regimes can be prolonged and stressful and have been shown to impact on the quality of life of children and their families (DiMatteo, 2004). This is particularly salient in the lives of CWE and their parents, given the unpredictability of epilepsy and sometimes unavoidable changes in treatment paths (Hazzard, Hutchinson, & Krawiecki, 1990). The imbalance seen here may suggest that CWE are in need of greater epilepsy-related communication and/or reassurance in times of medication difficulties.

9.1.2 Content of Epilepsy-related Communication

Both CWE and parents of CWE identified hospital appointments and antiepileptic medication as the most common topics of their epilepsy-related communication. It is not unexpected that the content of parent-child communication about epilepsy would focus on medication and hospital appointments; Hummelinck and Pollock (2006) have highlighted how parents of chronically-ill children seek to be knowledgeable of their child's medication and condition-management needs. Medication regimes are a part of daily life for children with chronic illnesses and their families (Gallo & Knafl, 1998). Indeed, the majority of the participants in the present study were engaged in a monotherapy or polytherapy treatment path, requiring CWE to take antiepileptic medication(s) daily. Adherence to daily medication regimes is of particular importance for CWE due to the threat of breakthrough seizures as a result of non-adherence (Glauser &

Loddenkemper, 2013). As primary information and guidance providers to CWE, it is important that parents are armed with the necessary level of detail relating to their medication treatment and hospital appointments in order to effectively impart this information to CWE during such discussions.

Conversations regarding antiepileptic medication and hospital appointments were not the only topics within which parents were tasked with explaining aspects of epilepsy to CWE. The quantitative findings reveal specific aspects of epilepsy that CWE seek information about and explanations surrounding. CWE highlighted the appearance of seizures as a key area for explanation, whereas parents identify the intrinsic query of "what epilepsy is" to be central to CWE's information needs. Parents must therefore not only be knowledgeable of day-to-day epilepsy-related events, but should also be equipped with easy-to-understand and age-appropriate explanations of the condition to impart to CWE. This finding supports the provision of child-friendly information for children with epilepsy and their parents in order to create ease of condition-specific communication and enhance overall understanding.

A sizable minority of participants reported not talking about; epilepsy-related restrictions that CWE experience (20% of parents and 38% of CWE), level of seizure control (38% of CWE), or growing out of epilepsy (15% of parents). Moffat et al. (2009) has previously highlighted parents imposing restrictions as a significant issue for CWE, however no previous studies have examined how CWE and parents may potentially communicate (or not) about this issue. This finding suggests that a lack of discussion occurs relating to epilepsy-related restrictions; however, this may also be due to CWE not experiencing activity restrictions at the time of questionnaire completion. Similarly, if CWE have a greater level of certainty around their seizure control, the topic may be of less relevance to them. Conversely, these topics may not be discussed because of difficulties CWE and parents experience in discussing these issues. Uncertainty surrounds issues of epilepsy-related activity-restriction and graduation from epilepsy with age, possibly identifying a reason for CWE's and parents' unwillingness to engage in dialogue relating to these topics.

9.1.3 Reasons for Epilepsy-related Communication

The most commonly reported reason for CWE to communicate about epilepsy with their parent(s) was a desire for no secrecy surrounding their condition. Over one third of CWE also reported talking about epilepsy with their parent(s) in order to feel greater informed about what to do if they experience a seizure, and about their condition overall. Research suggests that

people with epilepsy generally feel under-informed about their condition, with the majority of patients wanting more information about epilepsy following the initial diagnosis (Jain, Patterson, & Morrow, 1993). This, coupled with children's reliance on parents during engagements with HCPs (Wassmer et al., 2004; Tates & Meeuwesen, 2001), may lead CWE to seek further information when in a family context.

The majority of parents indicated that key reasons for them to talk to CWE about epilepsy was to inform them about their condition (89%), and in order for them to not bear secrecy surrounding the condition (78%). Though issues of secrecy and concealment surrounding childhood epilepsy (i.e. – not informing others external to the family context about CWE's epilepsy) have been documented previously (Schneider & Conrad, 1980; Jacoby & Austin, 2007), the link between parent-child communication and a desire to dispel secrecy surrounding epilepsy is a novel finding of the present study. This finding suggests that parents utilise epilepsy-related discussions to reinforce that epilepsy should be spoken about and not concealed, thus strengthening arguments for the use of parent-child communication about epilepsy as an effective coping mechanism for living with the condition.

Considering differences in CWE's and parents' reported reasons for engaging in dialogue about epilepsy, using communication to normalise epilepsy differed for CWE and parents. A sizeable number of parents (85%) indicated that helping CWE to avoid feelings of differentness was a key reason to talk to them about epilepsy. However, only 1 in 5 CWE rated this as a reason to engage in parent-child dialogue about epilepsy. It is widely acknowledged that children living with chronic illnesses, including epilepsy, grapple with feelings of differentness and normalcy seeking in light of their condition (Elliott et al., 2005; Fernandes et al., 2007; Lambert & Keogh, 2015). To the author's knowledge, this is the first study to report parents' use of parent-child communication a way to alleviate CWE's feelings of differentness. Though parents sought to normalise CWE's epilepsy by discussing the condition with them, findings suggest that CWE may not have been receptive to this approach with only 22% of CWE indicating that they sought to talk about epilepsy for this reason. It is therefore imperative for parents to be cognisant of the level and type of epilepsy-related communication CWE desire in order to encourage a sense of normalcy for CWE surrounding their condition.

9.1.4 Reasons against Epilepsy-related Communication

With regard to reasons against engaging in parent-child dialogue about epilepsy, 20% of CWE reported not wanting to cause their parents worry. CWE's awareness of their parents worry in

relation to their condition has been previously uncovered amongst CWE as young as 7 years (Moffat et al., 2009). CWE's fear of causing worry may result in them not seeking to engage in dialogue about epilepsy with their parents. The silence resulting from not wanting to cause worry could further perpetuate epilepsy-related worry for CWE and parents, resulting in a continuous cycle of epilepsy-related concern and little outlet to alleviate such concern via parent-child communication. Further associations uncovered relating to epilepsy-related worries and parent-child communication about the condition will be explicated in subsequent sections of this chapter.

With regard to parent perspectives, parents highlighted the possibility of CWE dwelling on their condition as a reason to not talk about epilepsy with them. Almost one third of parent participants stated that they would rather not engage in epilepsy-related conversations with CWE for this reason. To the author's knowledge, no previous studies have outlined a lack of parent-child communication due to parents not wanting CWE to dwell on the possible burden of having epilepsy. Parents' desire to keep CWE from having to deal with their epilepsy has been reported previously (Jantzen et al., 2009; Mu & Chang, 2010), however, the communicative processes at play to achieve this have not been investigated prior to the conduct of the present study.

9.1.5 Barriers to Epilepsy-related Communication

The most common barriers to engaging in epilepsy related communication for CWE were; their level of seizure control, and how they felt about epilepsy. Approximately 1 in 4 CWE indicated that how often they had seizures actively discouraged them from talking to their parents about their condition, and also identified their feelings towards epilepsy as a barrier to condition-related communication.

Findings linking CWE's seizure control to their likelihood to engage in parent-child communication about epilepsy echo previous findings relating to the context and content of CWE's discussions usually centring on epilepsy-related events. However, this particular finding highlights that CWE view their seizure control as an effective barrier to them talking about epilepsy with their parent(s). CWE may grapple with epilepsy-related concerns in times of lowered seizure visibility; however, they may face difficulties in communicating about epilepsy when symptomatic reminders are not present. Though Joachim and Acorn (2000a) have examined the impact of condition-visibility on communication with those external to the family unit, this further strengthens arguments relating to the roadblocks condition-visibility may cause

for parent-child communication about epilepsy. As I have alluded to in section 9.1.3, a key reason for CWE to engage in a dialogue about epilepsy with their parent(s) is to gain more knowledge about their condition. Communication interventions aimed at families of CWE should seek to break down the barrier that epilepsy invisibility presents in an effort to ensure that all CWE feel sufficiently informed about their condition, regardless of their level of seizure control.

Considering parents' perspectives, barriers to epilepsy-related communication existed for some parents relating to public perceptions of the condition. Portrayals of epilepsy in the media were a barrier to talking about epilepsy for 17% of parents, and parents' past experiences of epilepsy prior to CWE's diagnosis acted as a barrier for 13% of parents. Though small in numbers compared to other emergent findings, these barriers demonstrate the ongoing and real threat that public perceptions of epilepsy and epilepsy-related stigma present to CWE and parents dialoguing about the condition together. Though the impact of public misconceptions and epilepsy-related stigma on communicating about epilepsy with non-family members has been commented upon the research literature (Scambler & Hopkins, 1986; Joachim & Acorn, 2000a; Kılınç & Campbell, 2009), to the author's knowledge this is the first study to investigate the associations between parent perceptions of epilepsy-related stigma and the level of communication about epilepsy they engage in with CWE.

9.1.6 Enablers of Epilepsy-related Communication

The level of knowledge CWE and parents had about epilepsy was reported as the most common enabler of parent-child communication about epilepsy. The level of knowledge CWE have in relation to their epilepsy is often obtained from parental figures following engagements with HCPs (Austin et al., 1998). Therefore, parent knowledge about epilepsy is of critical importance for effective parent-child communication about the condition. Lack of parent information and parents' fear of misguiding CWE in relation to their condition have been outlined previously as struggles for parents of CWE (McNelis et al., 2007; Hirfanoglu et al., 2009; Jantzen et al., 2009). Additionally, evidence in support of educational-based interventions for families of CWE have been recorded (Jantzen et al., 2009), with some clearly demonstrating the benefit of greater levels of epilepsy-related information for overall family functioning (Austin et al., 2002). The information reported in the present study substantiate these findings by providing support for parent knowledge surrounding epilepsy aiding in a higher level of family functioning, via a greater level of parent-child communication.

CWE's seizures being well controlled also acted as an enabler for the majority of parent participants (68%). Previous research suggests that seizure frequency has a bearing on the level of epilepsy-related communication undertaken in the home, with lesser communication occurring in times of greater seizure freedom (Hodgman et al., 1979). Conversely, the present study provides evidence of parents' feeling greater enabled to talk to CWE about epilepsy in times of fewer seizures and a greater level of seizure control.

9.1.7 Consequences of Epilepsy-related Communication

The main consequences of engaging in epilepsy related communication for CWE were feeling happy and brave. However, almost 1 in 3 CWE relayed feelings of worry following such communication. It is important to ascertain what elements of parent-child conversations about epilepsy may result in CWE feeling a greater level of worry. Findings of the present study have suggested that CWE often talk to their parent(s) about their condition in order to gather epilepsy-related information, however, previous research suggests that CWE may also be susceptible to picking up parental cues with regard to how to view their condition (Scambler & Hopkins, 1986). CWE have been previously demonstrated to be cognisant of their parents' level of worry in relation to their epilepsy (Moffat et al., 2009). According to Bronfenbrenner's (1979) social-ecological systems theory, parent-child interactions are crucial to a child's emotional wellbeing and feelings of safety. Parental worry in relation to epilepsy may be conveyed to CWE by way of parent-child communication, causing them to worry about their condition. It is imperative for parents' to receive guidance regarding how to communicate openly about epilepsy and also tackle sensitive unpredictable epilepsy-related issues in a way that will not provoke concern amongst CWE.

With regard to the consequences of parent-child communication identified by parents, feelings of reassurance and optimism were most widely reported. However, parent-child communication had the potential to cause greater levels of concern amongst some parents of CWE with almost one third relaying feelings of anxiety in response to epilepsy-related communication. Jantzen et al. (2009) have previously demonstrated parents' development of irrational anxiety in relation to CWE's epilepsy. The present findings suggest that such anxiety may also be born from parent-child discussions about epilepsy. It is of crucial importance to tackle parent anxiety surrounding epilepsy, as a typical response of such anxious emotions is parental overprotection or hypervigilance (Jantzen et al., 2009; McEwan et al., 2004).

A dearth of literature surrounds the influence of parent-child conversations about epilepsy on CWE and parents emotions. It may be cautiously assumed from these findings that parent-child communication about epilepsy yields positive outcomes for CWE and parents, however, questions remain regarding what elements of CWE's and parents' epilepsy-related discussions evoke negative feelings of worry and anxiety. Relationships uncovered between parent-child communication about epilepsy and CWE and parent psychosocial wellbeing discussed in the following sections of this chapter will shed further light on the consequences of talking about epilepsy.

9.2 The Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy Measure

The Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy measure was developed in order to assess the positive and negative affect experienced by CWE following epilepsy-related discussions with parents. The process of developing this measure has been outlined previously in section 7.4.1 of Chapter seven. The need for this measure emerged from the qualitative phase which highlighted differing levels of affect for CWE following parent-child epilepsy-related conversations. In order to pinpoint the most beneficial epilepsy-related communication patterns for positive outcomes in CWE, the level of affect experienced by CWE was of particular interest and importance. No prior pre-validated instrument to measure the level of affect experienced by CWE following epilepsy-related discussion was identified within the research literature. Given the importance of this measure for the present study, and a dearth of adaptable affect measures existing within other chronic illness research, the decision was made to develop a new measure to tackle this research objective relating to the consequences of parent-child communication about epilepsy for CWE.

The level of affect experienced by parents following epilepsy-related communication with CWE was also of interest within the present study. However, unlike CWE, the qualitative findings of the present study suggest solely positive affect for parents (feeling greater-informed about epilepsy) following epilepsy-related discussions with CWE. This was reinforced by parent respondents indicating a largely positive affect of talking about epilepsy with CWE during this quantitative phase. Due to homogeneity in the levels of affect reported by parents in this phase of the study, (although possibly also as a result of the relatively sample size), not enough variance existed within the parent results to warrant the development of a parent version of this measure.

The Perceived Positive and Negative Affect of Parent-Child Communication about Epilepsy measure represents a unique and positive contribution to the field of epilepsy research, specifically research conducted with CWE, as it provides the first opportunity to measure the effect of epilepsy-related communication within the home for CWE. At present, no other instrument exists to measure the level of affect experienced by CWE following parent-child discussions about their condition. Indeed, comprehensive measures specifically examining parent-child communication about chronic illness are sparse within the research literature, instead a focus exists on family functioning (of which family communication may be a small counterpart) measures usually only incorporating parent-reports (Drotar, 1997). Drotar (1997) argues that research progress may be enhanced by the development of illness-specific and clinically-relevant measures.

Two primary advantages of this newly developed measure lie in; the use of CWE-report, and the specification of the measure to epilepsy. Historically, parent-proxy report measures have been favoured within psychosocial measurement in chronically-ill child populations (Le Coq, Boeke, Bezemer, Colland, & van Eijk, 2000; Palermo, Schwartz, Drotar, & McGowan, 2002; Warschburger, Landgraf, Petermann, & Freidel, 2003). As affect is such an objective and often non-explicit entity, this use of CWE report provides a more accurate account of the outcomes they experience following parent-child communication about epilepsy. Additionally, though epilepsy has been linked to research investigating other paediatric chronic illnesses such as diabetes (Houston, Cunningham, Metcalfe, & Newton, 2000) and asthma (Tieffenberg, Wood, Alonso, Tossutti, & Vicente, 2000), the unique characteristics of epilepsy must be acknowledged in order for comprehensive and accurate measurement to occur. Epilepsy differs to other chronic illnesses due to the unique level of invisibility, unpredictability, and uncertainly inherent within its symptomatology. By developing a measure seeking to examine the outcomes of parent-child communication about epilepsy specifically, the results uncovered may be more in-depth and attributable to solely CWE populations.

9.3 Associations between Epilepsy-related Communication and CWE Wellbeing

Associations uncovered between parent-child communication variables and a number of CWE-reported demographic, clinical, and psychosocial variables are discussed below.

9.3.1 Epilepsy-related Communication and CWE Demographic Characteristics

The present study found that CWE were less likely to experience positive affect, such as feeling happy and brave, following epilepsy-related communication with parents as they got older. Heimlich et al. (2000) have posited that CWE's perceptions of epilepsy may alter over time, possibly reflecting the increased importance placed on social desirability and peer acceptance in adolescence (Coleman & Hendry, 1990). Increased awareness of public perceptions of epilepsy with age, coupled with an increased understanding of the stigma that surrounds epilepsy as a condition (Scambler & Hopkins, 1986), may result in CWE viewing epilepsy in a more negative light. These negative perceptions may come to light more when engaging in communication about epilepsy, be that with parents or peer figures, resulting in CWE experiencing less positive emotions surrounding epilepsy-related communication.

9.3.2 Epilepsy-related Communication and CWE Clinical Characteristics

Considering the relationship between parent-child communication and CWE's clinical characteristics, CWE experiencing tonic clonic seizures talked to their mother more frequently about their condition than those who did not have tonic clonic seizures. Previous research has also shown that CWE generally speak to mothers about their epilepsy, with maternal figures known to take a dominant care role in families living with childhood epilepsy (Mulder & Suurmeijer, 1977; Ritchie, 1981; Kitamoto et al., 1988). Two reasons may contribute to why tonic clonic seizures were associated with greater mother-child communication; 1) the potential lack of understanding for CWE surrounding this seizure type (Baker, Spector, McGrath & Soteriou, 2005), and 2) the potential disruptiveness and stereotyping of this seizure type in a public setting (Westbrook, Bauman, & Shinnar, 1992). Tonic-clonic seizures present a challenging and potentially distressing event for CWE (Baker et al., 2005). CWE's need for support and information following a tonic clonic seizure may be heightened causing them to seek to talk to their mother about their condition/seizures. However, CWE experiencing tonic clonic seizures and ESES were also found to experience a greater level of negative affect following parent-child communication about epilepsy. This may indicate that CWE with these seizure types may leave conversations with parents feeling more sad, worried, embarrassed, or different. As has been reported previously, tonic-clonic seizures may cause potential disturbance and stereotyping of CWE if they occur in the public domain (Westbrook et al., 1992), potentially resulting in feelings of embarrassment or differentness for CWE. Furthermore, CWE experiencing ESES (characterised by the occurrence of seizures during sleep) may experience a

negative effect of worry following parent-child communication, possibly due to conversations centring on the possibility of CWE experiencing a seizure whilst sleeping.

9.3.3 Epilepsy-related Communication and CWE Psychosocial Wellbeing

The findings of a number of previously hypothesized relationships between parent-child communication and CWE psychosocial variables are discussed below.

CWE's Perceptions of Epilepsy

For the first time significant relationships have been uncovered relating to the way in which CWE talk about epilepsy within the home and their perceptions of their epilepsy. Hypotheses relating to parent-child communication and CWE perceived stigma and epilepsy-related attitudes were supported. CWE who perceive a greater level of epilepsy-related stigma attribute more negative feelings to talking about epilepsy with parents. Similarly, negative attitudes towards epilepsy amongst CWE were associated with both; greater negative affect following parent-child communication, and less perceived open communication within the family.

This novel evidence uncovered in the present study suggests that less communication about epilepsy between CWE and parents, and negative feelings following this communication, are linked to CWE perceiving their condition in a negative light and perceiving more epilepsy-related stigma. The factors influencing the development of felt stigma perceptions remain relatively unknown (Lee, Yoo, & Lee, 2005; MacLeod & Austin, 2003; Austin et al., 2004). The present study addresses this gap in the research literature by assessing the impact of parent-child communication about epilepsy and suggesting that such communication informs CWE's perceptions of their condition and may contribute to epilepsy-related stigma. Stigma perceptions in CWE are complex and encompass numerous social and personal factors (Austin et al., 2004). The development of CWE's attitude towards epilepsy, and epilepsy-related stigma, is critical to their adjustment to the condition (Heimlich et al., 2000) with evidence suggesting that negative attitudes are associated with increased behavioural problems and decreased self-competence (Austin & Huberty, 1993; Austin et al., 1998). Heimlich et al. (2000) suggest that older CWE are at particular risk of developing negative attitudes towards their epilepsy, potentially due to a greater awareness of epilepsy-related misconceptions and stigma in wider society. Therefore, identifying the role that parent-child communication plays in the formation of CWE's illness attitudes and stigma perceptions is important and warrants further research.

In terms of how the level of epilepsy-related communication parents engaged in and the parenting styles they adopted were associated with psychosocial wellbeing in CWE, an authoritative parenting style, facilitating open communication between parents and CWE, was associated with CWE holding positive attitudes towards their condition. As has been highlighted previously, a positive epilepsy-related attitude is associated with greater self-esteem and self-efficacy amongst CWE (Austin & Huberty, 1993; Heimlich et al., 2000). It is therefore desirable that CWE uphold a positive attitude relating to their epilepsy, and of importance to note that this may be facilitated by open parent-child communication about epilepsy. To the author's knowledge, the association between parent-child communication and the formation of illness attitudes amongst CWE is a novel finding of the present study. Given the positive outcomes for CWE linked with positive illness attitudes and less perceived stigma, such as greater self-esteem and greater self-efficacy (Austin & Huberty, 1993; Heimlich et al., 2000); parents should remain mindful of the links between their epilepsy-related communication with CWE and the formation of illness attitudes. By engaging in open communication about epilepsy, parents may encourage CWE to foster positive attitudes in relation to their condition and thus enhance the psychosocial wellbeing of CWE.

CWE's Self-Perception

Perceptions of the "self" have implications for one's day-to-day life, most notably in the lives of children and adolescents (Harter, 1999). Prior to the current study, however, no previous research has sought to identify the relationship between CWE's self-perception and their communicative behaviours with parents surrounding the condition. A number of parent-child communication variables were found to be both positively and negatively linked with CWE's self-perception (in the direction predicted), providing support for relevant hypotheses in the present study (see section 8.3.3 of Chapter 8). CWE in families facilitating more open communication reported greater social competence. Social competence here refers to confidence in knowing how to make friends and an understanding of what it takes to be popular in peer groups (Harter, 1985a). It has been reported previously that CWE possess lower social competence than non-chronically ill children (Whitman, Hermann, Black, & Chhabria, 1982), suggesting that making friends may present a challenge for CWE. However, the findings from the present study suggest for the first time that more open parent-child dialogue with CWE about their condition is linked to CWE holding more confidence in peer interactions, supporting the facilitation of open communication strategies surrounding epilepsy within a family context.

Negative associations with CWE's self-perception were also observed. CWE in families implementing more closed communication strategies were found to have a more negative self-perception of their behaviour. Additionally, CWE who reported greater levels of negative affect following parent-child communication about epilepsy were found to hold a more negative self-perception in terms of their social interactions, their behaviour, and their self-worth. The relationship between closed communication (and negative affect of epilepsy-related communication with parents) and negative self-perceptions amongst CWE has not been uncovered in the literature previously. Given the importance of self-perception as an index for positive outcomes in later life (Muris, Meesters, & Fijen, 2003), the negative implications of closed communication strategies and the positive implications of open communication strategies to epilepsy within the home carry considerable weight. By opening channels of communication in relation to epilepsy within the home, CWE may feel better enabled to interact socially with peers external to the family unit.

CWE's Health-related Quality of Life

The health-related quality of life of individuals with epilepsy has historically been the focus of numerous research studies seeking to examine the impact of the condition (Drotar, 2014; Ferro et al., 2013; Devinsky et al., 1999; Johnson, Jones, Seidenberg, & Hermann, 2004; Leidy, Elixhauser, Vickrey, Means, & Willian, 1999). However, no studies have sought to investigate how parent-child interactions about epilepsy may promote, or infringe upon, optimal health-related quality of life amongst CWE. Predicted relationships were observed between CWE's parent-child communication reports and health-related quality of life, providing support for the hypothesis that CWE in families facilitating open communication about epilepsy would have greater health-related quality of life (see section 8.3.3 of Chapter 8). Findings revealed that CWE of parents who facilitate more open communication, and who experienced greater positive emotions following this communication, reported less need for normality surrounding their epilepsy. The struggle that a desire for normalcy presents in the lives of CWE has been commented upon previously (Schneider & Conrad, 1980; Scambler & Hopkins, 1986; Kılınç & Campbell, 2009). To the author's knowledge, this is the first study to quantitatively link a lowered perceived need for normalcy with open parent-child communication in a CWE population. These findings suggest that feelings of differentness harboured by CWE may be reduced with the facilitation of open communication about epilepsy within the home. In contrast, CWE who reported greater levels of epilepsy-related communication with fathers reported a greater need for secrecy surrounding their epilepsy. Evidence exists in previous

research suggesting that fathers take a less important role in the care of CWE in comparison to mothers (Ritchie, 1981); with one study demonstrating fathers holding rejecting attitudes towards CWE (Mulder & Suurmeijer, 1977). The attitude held by fathers of CWE during epilepsy-related engagements may provide one reason for this conflicting finding. However, this finding must be cautiously interpreted given the relatively low number of fathers participating in the present study.

Findings of the present study also unveiled the negative impact of closed communication and negative affect for CWE's health-related quality of life. CWE within families implementing closed communication strategies, or CWE who attributed more negative emotions following communicating about epilepsy with parents, reported; a greater number of interpersonal and social consequences relating to epilepsy, a greater level of emotional issues, a desire for concealment and secrecy surrounding epilepsy, and a greater need for normality surrounding epilepsy. These findings suggest for the first time that CWE in families where epilepsy-related communication was closed and infrequent perceived a greater impact of epilepsy on their quality of life and wellbeing.

Interestingly, closed communication (perpetuated by an authoritarian parenting style) was associated with a higher level of epilepsy-related worries and concerns for CWE. This may be due to a lack of opportunity for CWE to discuss their epilepsy-related concerns with parents, and therefore these concerns remaining unalleviated. Parent-child communication about chronic illnesses, such as epilepsy, can aid children and parents in effectively coping with the condition (Cohen, 1999). CWE in families in which closed communication abounds are not in receipt of these potentially beneficial coping mechanisms and therefore may feel less supported and more burdened by their condition. The associations observed between closed communication strategies and poor health-related quality of life bear strong implications for guiding parents in communicating about epilepsy with CWE.

CWE's Perceived Level of Support

Positive associations were identified between CWE attributing more positive emotions to talking about epilepsy with parents and their perceived social support from teacher figures. Additionally, CWE of families facilitating more open communication also reported a greater level of perceived social support from their classmates. Conversely, CWE in families with more closed communication relating to epilepsy, and CWE who attributed more negative feelings to communication about epilepsy with parents, relayed less perceived social support from

classmates, teachers and parents. Family support is essential to instilling positive coping mechanisms at the outset and during acute phases of illness (Rait et al., 1992). Empirical research suggests that parents of CWE are the key providers of information and support to CWE in relation to their condition (Coulter & Koester, 1985; Austin et al., 2002; Hirfanoglu et al., 2009; Jantzen et al., 2009). The present study extends this evidence further by suggesting that CWE perceptions of less social support from parents are correlated with less engagement in communication about epilepsy. These findings represent the first time that an association has been uncovered between parent-child communication strategies surrounding epilepsy and perceived social support both within the family (parental support) and external to the family context (classmate and teacher support).

CWE who reported more negative feelings surrounding parent-child communication about epilepsy also reported a greater need for epilepsy-related support. As many as 1 in 5 CWE have been previously reported as not having enough support from their family members (Hirfanoglu et al., 2009). Interestingly, however, no relationships were uncovered between parent-child communication and CWE's need for information in the present study. Therefore, even in cases where CWE feel sufficiently informed about their condition, they may still feel fundamentally unsupported and this may have a greater impact upon their willingness to engage in parent-child dialogue about epilepsy. This finding emphasises the multi-faceted nature of epilepsy-related support that CWE may require; rather than informational support, CWE also may be in need of emotional and infrastructural support in relation to their condition.

9.4 Associations between Epilepsy-related Communication and Parent Wellbeing

Associations uncovered between parent-child communication variables and a number of parent-reported demographic, clinical, and psychosocial variables are discussed below.

9.4.1 Epilepsy-related Communication and Parent Demographic Characteristics

Parent gender and education level were found to be significantly associated with the style of parenting adopted, with fathers and parents with a lower level of education attained more likely to adopt a permissive parenting style. Permissive parenting styles are characterised by a low level of communication between parent and child (Johnson & Kelley, 2011). Therefore, fathers and parents with lower education levels were found to communicate with CWE less within the home. This finding substantiates research stating that mothers were generally the chosen figure for CWE to converse with about their condition (Ritchie, 1981). Mulder & Suurmeijer (1977)

also found that fathers of CWE had a rejecting attitude towards CWE's epilepsy, perhaps discouraging them from engaging in epilepsy-related dialogue with CWE.

Considering the factor of parent education level, previous research in the area of childhood chronic illness has found that chronically ill children whose parents have a higher level of education are socially more active and experience less anxiety in social situations (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). Therefore, parents with a lower education level who adopt a permissive parenting style and engage in less communication may result in CWE being less socially active even within the parent-child relationship.

9.4.2 Epilepsy-related Communication and CWE Clinical Characteristics (Parent-Reported)

Few clinical aspects of CWE's epilepsy were associated with parents' reports of parent-child communication. CWE seizure type was associated with differing parenting styles, with parents of CWE experiencing absence seizures more likely to report the adoption of an authoritative style than parents of CWE not experiencing absence seizures. An authoritative style is one in which value is placed on parent-child communication and a high level of responsiveness (Maccoby & Martin, 1983). Authoritative parenting has been widely related to positive child and adolescent adjustment (Steinberg, Mounts, Lamborn, & Dornbusch, 1991; Kaufmann et al., 2000). This finding builds on research suggesting that CWE experiencing absence seizures experience more positive adjustment to epilepsy compared to other seizure types (Olsson & Campenhausen, 1993). Similarly, parents of CWE with absence seizures who experience positive adjustment to the condition may engage in open parent-child dialogue about epilepsy with greater ease.

Conversely, parents of CWE experiencing myoclonic seizures reported the adoption of more authoritarian styles of parenting. An authoritarian parenting style is characterised by strictness and a lack of communication between parent and child, usually facilitating closed communication strategies within the family unit (Darling & Steinberg, 1993; Robinson et al., 1995). The present study is the first to unearth an association between CWE's clinical characteristics and the style of parenting adopting by their parents. Future research should endeavour to examine the association between seizure types and the level of value placed by parents on communication with CWE about epilepsy.

9.4.3 Epilepsy-related Communication and Parent Psychosocial Wellbeing

The findings of hypothesized relationships between parent-child communication and parent psychosocial variables are discussed below.

Parents' Perceptions of Epilepsy

Parents who reported higher levels of perceived epilepsy-related stigma endorsed a more authoritarian parenting style. Therefore, parents who perceive a greater level of stigma generally engaged in communication to a lesser extent with CWE, thus providing support for the hypothesised relationship. Parental perceptions of epilepsy-related stigma have been documented in a number of studies (Scambler & Hopkins, 1986; Austin et al., 1998; Austin et al., 2004). Investigations seeking to understand how parents may relay perceptive cues relating to epilepsy-related stigma to CWE are crucial as the exposure of CWE to heightened stigma perceptions can place them at risk for problematic behavioural and emotional outcomes in later life (Carlton-Ford et al., 1997). These findings highlight the necessity of parents to be cognisant of the perceptive cues they may relay to CWE surrounding their condition via the style of communication they engage in when talking about epilepsy.

Parental attitudes and responses to CWE's epilepsy were also associated with the level of epilepsy-related communication parents engaged in with CWE. Parents who reported the adoption of an authoritative parenting style (typically valuing open parent-child communication) also reported a more positive parent response to CWE's epilepsy and the provision of greater emotional support for CWE. Additionally, parents who engaged in a greater level of communication about epilepsy with CWE had more confidence in managing the condition, and encouraged CWE's autonomy and independence. Parents endorsing an authoritative parenting style typically provide children with love, care and emotional support whilst also establishing what infers appropriate behaviour (DeHart, Pelham & Tennen, 2006). It is therefore unsurprising that such parents sought to offer CWE greater levels of emotional support in light of their condition. Though unsurprising, this finding presents a previously undocumented association between a positive response to child epilepsy and the adoption of an authoritative parenting style. Greater parental encouragement of CWE autonomy has previously been related to an increase in parent knowledge relating to epilepsy (McEwan et al., 2004; Hirfanoglu et al., 2009). However, this is the first empirical link established between greater levels of parent-child communication and encouragement of CWE independence.

Interestingly, a poorer illness-attitude, less parental confidence in managing epilepsy, less participation in activities as a family, and less encouragement of CWE autonomy were associated with the adoption of authoritarian and permissive parenting styles, both typically dismissive of parent-child communication. Hirfanoglu et al. (2009) have alluded to how greater CWE autonomy can have a positive impact on epilepsy-related parent-child relations, however, the present findings bring to light the potential implications of a poor parental illness attitude for the family as a whole. By facilitating a greater level of support and confidence in epilepsy-management amongst parents, channels of communication pertaining to epilepsy may be opened between CWE and parents.

Aside from examining relationships between parent-reported communication strategies and parents' psychosocial wellbeing, exploratory analyses were also conducted across CWE's reported parent-child communication strategies and parents' psychosocial wellbeing. Aspects of parents' response to CWE's illness were positively associated with CWE-reported parent-child communication, with mothers who were more confident in managing CWE's epilepsy engaging in a greater level of epilepsy-related communication with CWE. Conversely, parents who were less confident in managing CWE's condition engaged in less open communication with CWE, from a CWE perspective.

Considering other aspects of how parents responded to CWE's epilepsy, less parental encouragement of CWE autonomy was associated with CWE attributing more negative feelings to talking about epilepsy with parents. Indeed the issue of lacking autonomy and parental hypervigilance has been reported as a significant frustration for CWE (Hodgman et al., 1979; Hirfanoglu et al., 2009; Jantzen et al., 2009; McEwan et al., 2004). Parent-child conversations relating to this frustration may evoke CWE to experience negative emotions when talking about epilepsy. To the author's knowledge, this is the first study to highlight the association between parents' lack of encouragement of CWE autonomy and negative affect of talking about epilepsy for CWE.

CWE of parents who perceived a greater impact of epilepsy (on CWE and the family as a whole) were more likely to experience negative feelings following communication about epilepsy with their parent(s). DeBoer, Mula, & Sander (2008) have posited that the impact of epilepsy is not only borne by the individual themselves but also by family members who may view the condition as a burden. This novel finding may be due to parents relaying a perceived burden of epilepsy to CWE via parent-child dialogue about the condition.

Parents' Perceived Level of Support

The levels of social support parents of CWE perceived from friends and family were strongly associated with their style of parenting. Parents who reported high levels of support from friends were likely to engage in authoritative parenting (valuing open parent-child communication). However, lower perceived support from family and friends were linked to the adoption of a permissive parenting style (characterised by a low level of parent-child communication). This is the first study to examine the association between perceived social support and epilepsy-related communication within a family context. Research conducted with parents of children with disabilities has alluded to the way in which parents' supportive networks can mediate parents' perceptions of their child's behaviour, as well as their felt need for overprotection of the child (Dunst, Trivette, & Cross, 1986). This may have a beneficial effect on family functioning overall; encouraging more open communication between parents and children (as would be typical within authoritative parenting) (Armstrong, Birnie-Lefcovitch, & Ungar, 2005). Further research amongst families of CWE is necessary to explicate the relationship between parents' perceived social support and parent-child communication about epilepsy and to ascertain the beneficial potential of parental social support in facilitating open communication about epilepsy within the parent-child dyad, or vice versa.

Authoritative parenting styles were less likely to be adopted if parents were in greater need of epilepsy-related support, indicating that parents who felt under-supported with regard to CWE's condition were less likely to engage in open communication about epilepsy with CWE. This finding echoes CWE's need for support in relation to epilepsy and the barrier this creates for open communication about epilepsy within the home. Parents who feel under-supported may feel ill-equipped to support CWE in relation to their condition (Armstrong et al., 2005), and may not engage in parent-child communication about epilepsy. The novel association between parents' need for support and their adoption of closed parenting styles surrounding epilepsy should be examined further to ascertain potential outcomes of this strategy for CWE.

9.5 Strengths and Limitations of the Quantitative Phase

To the author's knowledge, this is the first time that the relationship between parent-child epilepsy-related communication and CWE's and parents' psychosocial wellbeing has been quantitatively explicated. A major strength of the quantitative investigation is the inclusion of both CWE and parent perspectives, as parent-proxy reports are typically used within illness-related psychosocial research (Sherifali & Pinelli, 2007). Furthermore, the inclusion of a newly

developed Parent-Child Communication about Epilepsy Questionnaire has elucidated novel knowledge relating to the way in which CWE and parents' communicate about epilepsy together and presents a valuable contribution to future quantitative research with CWE populations.

Despite the aforementioned strengths, it is also important to acknowledge some limitations of the quantitative phase. The relatively small sample size accessed for this phase of the study presents a methodological limitation. Additionally, the majority of parent participants in this phase were mothers, potentially limiting the transferability of these findings to fathers of CWE. With regard to the sample of the quantitative study, strategies were instigated by the researcher to increase the sample size as much as possible. These strategies included; 1) expanding recruitment sites for this phase to include three paediatric and/or neurology units and Epilepsy Ireland, and 2) the inclusion of two follow-up letters sent to families seeking to maximise questionnaire response rates. Despite these attempts to increase the study sample size, numbers participating in this quantitative phase remained small. Future research should seek to address this limitation by replicating the findings with larger sample sizes.

9.6 Conclusions of the Quantitative Phase

Findings from the quantitative phase of this study have highlighted, for the first time, specific information relating to the primary context, content, reasons for and reasons against, barriers, enablers, and consequences of engaging in parent-child dialogue about epilepsy. Variance in the level of communication engaged in, the strategies employed, the affect experienced, and the parenting styles incorporated have been observed. Open communication strategies yield more positive associations to CWE's and parents' psychosocial wellbeing than more closed communication approaches. Open communication has been linked to; less perceived stigma for CWE and parents, a positive illness attitude for CWE, a positive response to illness for parents, a positive self-perception for CWE, greater health-related quality of life for CWE, more perceived social support for CWE and parents, and less need for epilepsy-related support for CWE and parents. Closed communication has, conversely, been associated with; greater perceived stigma for CWE and parents, a poorer illness attitude for CWE, a negative response to illness for parents, a negative self-perception for CWE, poorer health-related quality of life for CWE, less perceived social support for CWE and parents, and greater need for epilepsy-related support for CWE and parents.

The relationships uncovered between parenting styles and CWE/parent wellbeing encapsulate the overall trend for a greater level of communication and an authoritative parenting style to be

linked to more positive psychosocial outcomes for both CWE and parents. A greater level of communication and/or the adoption of an authoritative parenting style have been associated with; greater confidence in managing epilepsy, greater encouragement of CWE autonomy, a more positive response to CWE's condition, greater provision of epilepsy-related support for CWE, greater perceived social support, and less need for epilepsy-related support. Furthermore, evidence from these analyses has shown the risks that closed communication, authoritarian, and permissive parenting styles present for CWE's psychosocial adjustment. Less communication, authoritarian, and permissive parenting have been linked to poorer outcomes, such as; greater perceived stigma, poorer illness-attitudes, a more negative response to CWE's condition, less affordance of autonomy to CWE, less provision of epilepsy-related support for CWE, less confidence in managing CWE's behaviour, greater epilepsy-related worries and concerns for CWE, less family participation in activities, and lower perceived levels of social support.

For the first time, a relationship between parent-child communication and CWE/parent psychosocial wellbeing has been uncovered within this study. With this novel knowledge now unearthed, the author may cautiously assume that open communication relating to epilepsy should be advocated as the most beneficial strategy for CWE and parents when talking about epilepsy. Findings relating to parental confidence in condition-management and encouraging CWE autonomy pinpoint particular constructs that may be implicated within a family-based communication intervention for CWE and their parents. These implications are two fold; 1) HCP's should seek to provide parents of CWE with sufficient levels of epilepsy-related information and support, particularly at the time point of diagnosis, and therefore potentially lessen the impact of epilepsy perceived by parents and increase confidence in their condition-management abilities, and 2) parents should seek to afford CWE a greater level of autonomy despite possible restrictions imposed by their condition. An intervention including these measures may promote a greater and more open level of parent-child communication about epilepsy within the home. The findings of this quantitative phase will be integrated with the findings uncovered via the initial qualitative phase in the following chapter in order to provide a more in-depth overview of the key findings uncovered in this mixed-method study.

Chapter 10: Integrative Discussion

10.0 Introduction

This chapter will present a detailed discussion of the integration of findings from phase one and phase two of the present study. The chapter will begin with a description of how the qualitative and quantitative findings were integrated. The integration of CWE and parent findings across both phases of the study will then be detailed. Finally, the key findings of the mixed-method study will be discussed.

10.1 Integrating the Qualitative and Quantitative Findings

The process of integrating data from the first and second phases allowed for several possible outcomes; convergence (where both data sets produce the same finding on a theme); complementarity (where both data sets feature a theme but have differing perspectives on that theme); silence (where one data set uncovers a theme whereas it appears silent in the other data set); and discrepancy (where the data sets have conflicting findings on a theme) (Farmer et al., 2006). This process of integration allows for further support and elaboration of particular themes throughout the data. Further detail relating to the data integration process has been provided in section 3.4.1 of Chapter 3.

10.2 Discussion of Integrated Findings

In response to the overarching research questions posed by this mixed method study, findings were integrated according to seven categories. These categories were; 1) communication strategies, 2) context of communication, 3) content of communication, 4) barriers to communication, 5) enablers of communication, 6) consequences of communication, and 7) the relationship between parent-child communication and psychosocial wellbeing. No discrepancies between the findings of different phases were uncovered in the present study; convergent, complementary, and silent themes were identified.

10.2.1 Epilepsy-related Communication Strategies

Four communication strategies used by CWE were identified across both qualitative and quantitative findings; open, supportive, closed, and limited communication. Findings relating to these four communication strategies were convergent in nature (See Figure 10.1).

Six communication strategies used by parents were identified in total. Four communication strategies were reported within both the qualitative and quantitative phases of the present study; open communication, supportive communication, closed communication, and limited communication. Findings relating to these four communication strategies present in both study phases were convergent in nature. The remaining two communication strategies of avoidant and influential communication were solely present within the qualitative phase and therefore silent in nature, however, it is recognised that this may be due to the specific quantitative instruments used not accessing these strategies in parents (See Figure 10.1).

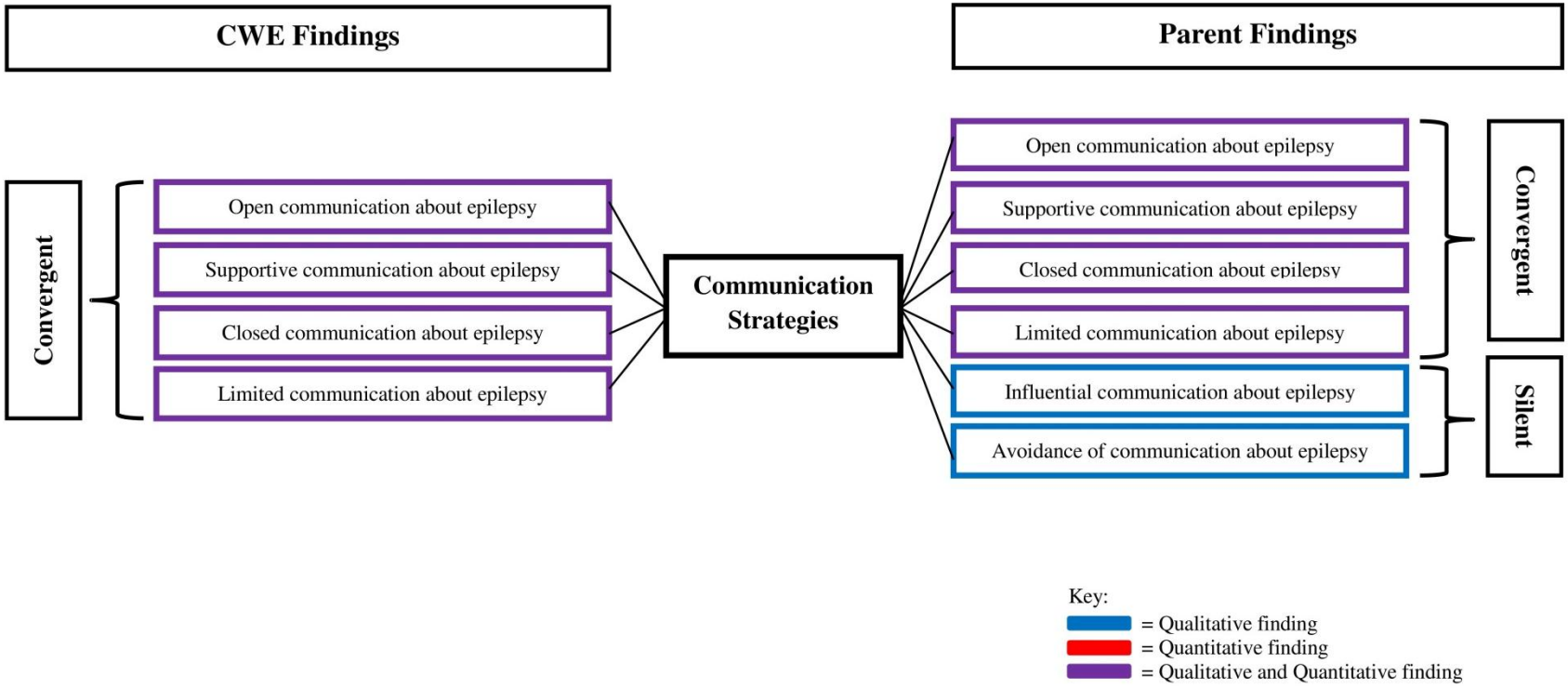


Figure 10.1: ***Epilepsy-related Communication Strategies: Integrated Findings***

10.2.2 Context of Epilepsy-related Communication

Five contexts in which CWE engaged in epilepsy-related dialogue with parents were identified. Two of these contexts were present across the qualitative and quantitative phases; communication before or following CWE's hospital appointments, and communication following seizures. Findings relating to these themes were convergent in nature. Two contexts were solely relayed in the qualitative phase; the fact that parent-child communication about epilepsy generally occurred spontaneously, and was largely dependent on CWE's level of seizure control. Finally, the quantitative phase gave rise to one additional context; communication when CWE's antiepileptic medication caused difficulty (See Figure 10.2).

Five contexts in which parents talked about epilepsy with CWE were identified. Three contexts occurred across both phases of the present study; communication before or following CWE's epilepsy-related appointments (convergent findings), communication when CWE had a question (complementary findings), and communication when CWE needed support (complementary findings). The themes of communication not being pre-planned, and communication being linked to CWE's seizure control were silent; found to only occur in the qualitative study (See Figure 10.2).

An overarching theme relating to the context of CWE's and parents' epilepsy-related discussions is the visibility of epilepsy within the home. Conversations relating to epilepsy were contingent on epilepsy-related events occurring in the lives of CWE, for example, hospital appointments or seizures. This theme was unearthed from both CWE and parent perspectives, with condition-visibility behaving as a catalyst for epilepsy-related conversations across the data. Furthermore, contexts in which parents aimed to provide CWE with information, guidance, and support relating to their epilepsy were also uncovered as critical times in which the condition was talked about. This solidifies parents' role as key information provider for CWE in relation to their condition and highlights the necessity of parents to be knowledgeable of their child's epilepsy condition. Key issues of condition visibility and epilepsy-related knowledge are further discussed in sections 10.3.1 and 10.3.2 of this chapter.

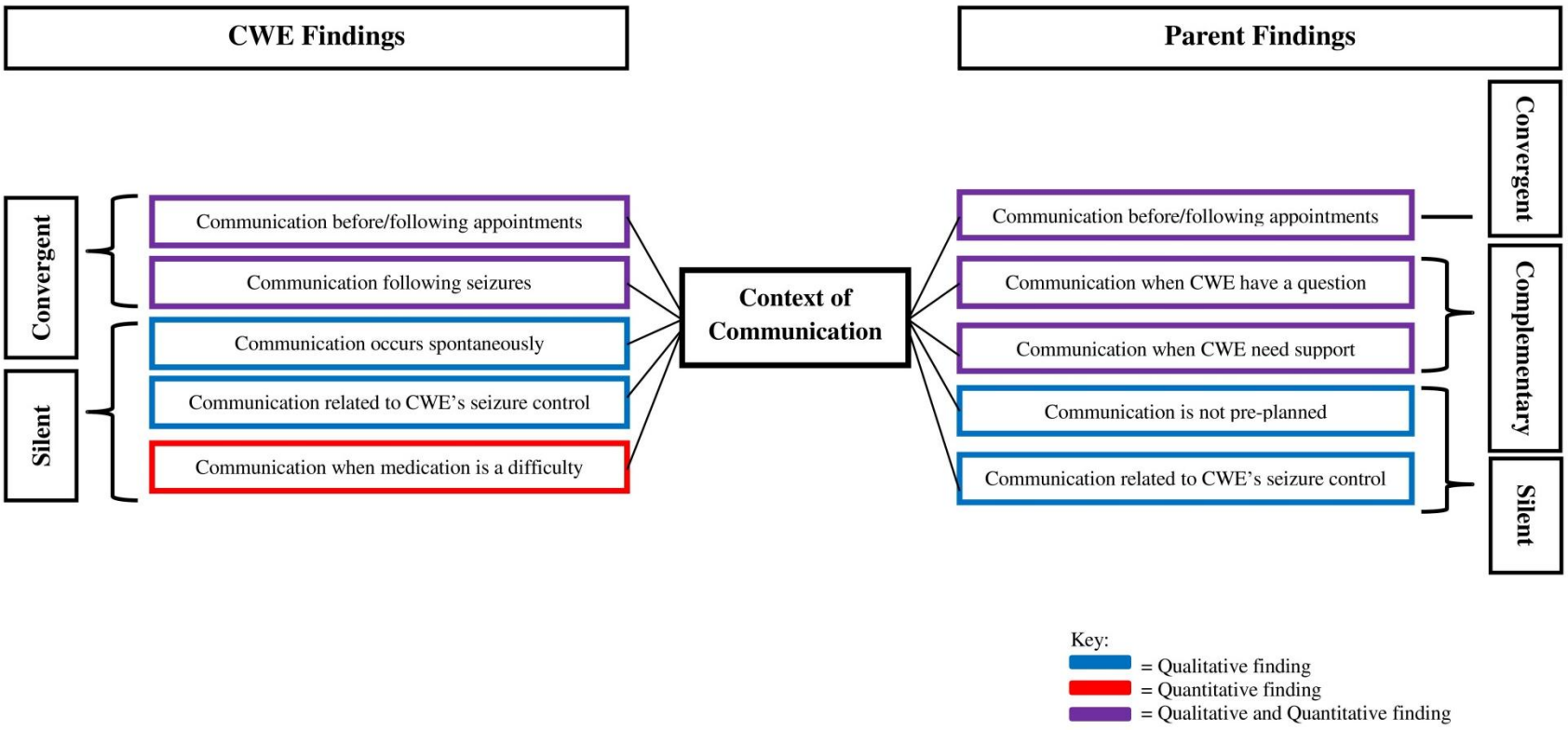


Figure 10.2: ***Context of Epilepsy-related Communication: Integrated Findings***

10.2.3 Content of Epilepsy-related Communication

Seven epilepsy-related topics of conversation were identified by CWE in total. Five of these topics were conveyed across both phases of the study; CWE's antiepileptic medication (convergent findings), hospital appointments (convergent findings), epilepsy-related events (complementary findings), gaining explanations of epilepsy (complementary findings), and the manifestation of seizures (complementary findings). Two remaining topics were silent in nature; growing out of epilepsy, and public perceptions of epilepsy (See Figure 10.3).

For parents, nine topics about epilepsy-related communication with CWE were identified. Five topics occurred across both phases of the study; CWE's antiepileptic medication (convergent findings), CWE's hospital appointments (convergent findings), explaining of epilepsy (complementary findings), epilepsy-related reassurance (complementary findings), and epilepsy-related events (complementary findings). The remaining four topics of conversation identified by parents were all silent in nature; the manifestation of seizures, growing out of epilepsy, disclosing epilepsy, and public perceptions of epilepsy (See Figure 10.3).

The topics of CWE's and parents' epilepsy-related conversations predominantly centred on epilepsy-related events CWE were experiencing, such as hospital appointments and medication routines. Overall findings suggest that CWE and parents may communicate about epilepsy-related events beforehand in order to prepare CWE, or afterward in order to discuss these events together. This finding further substantiates evidence relating to condition visibility by explicating that CWE and parents generally spoke about epilepsy-related issues that were "visible" at the time of communicating. Integrated findings also reveal that parents provided CWE with information and reassurance in relation to their condition. Though quantitative findings support that these topics were common amongst CWE and parents, qualitative findings provide complementary insights relating to specific areas in which CWE sought information. Examples of such areas include explanations of epilepsy (including causes of the condition) and how seizures appear to others. As parents are commonly tasked with explaining epilepsy to CWE in a child-friendly manner, parent knowledge relating to epilepsy is of utmost importance for effective parent-child communication. These key findings of condition visibility and epilepsy-related knowledge will be further discussed in sections 10.3.1 and 10.3.2 respectively.

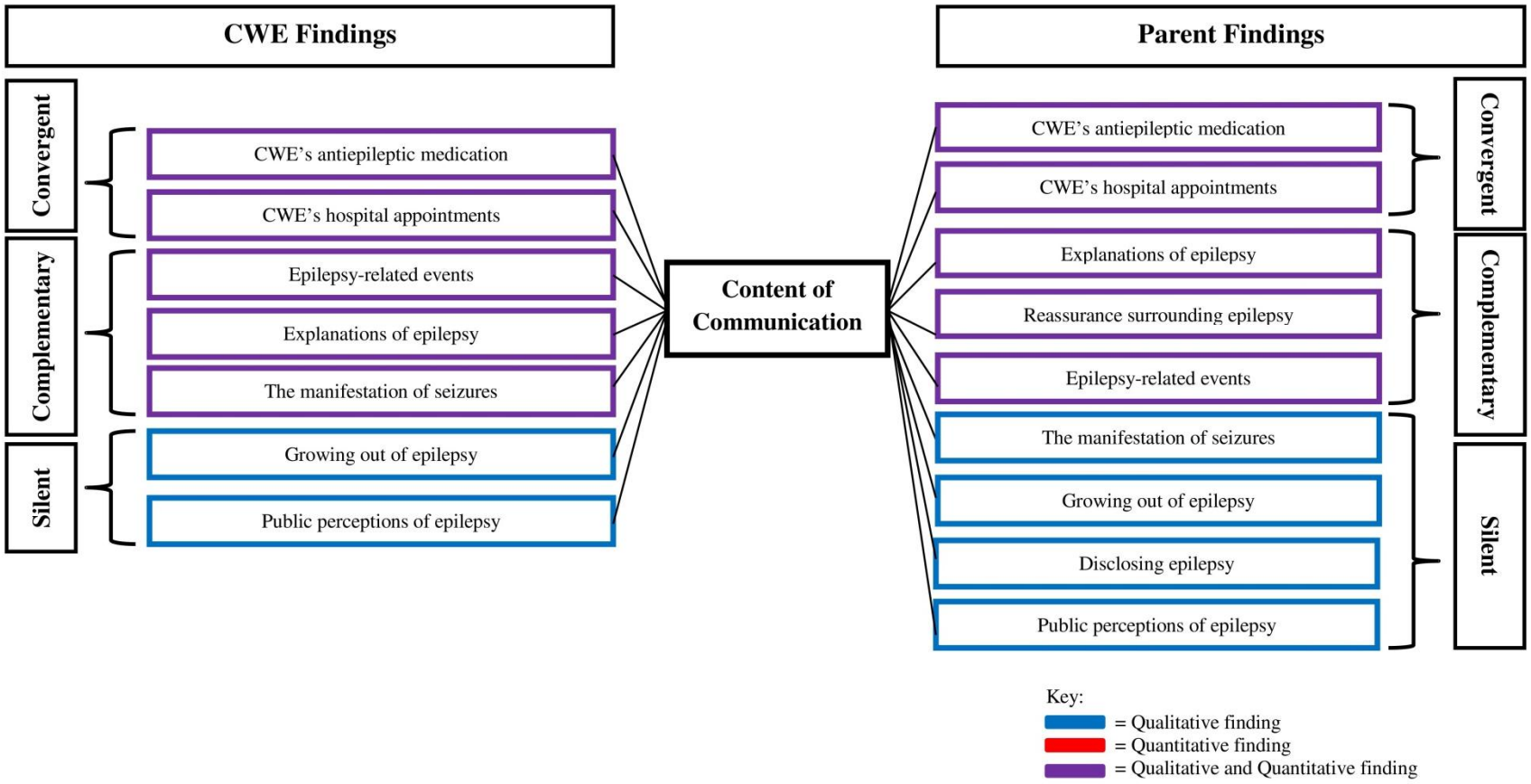


Figure 10.3: ***Content of Epilepsy-related Communication: Integrated Findings***

10.2.4 Barriers to Epilepsy-related Communication

Integration of the qualitative and quantitative findings revealed seven barriers to communication perceived by CWE. Four barriers occurred across both phases of the present study; avoiding activity restrictions (convergent findings), not wanting to worry parents (convergent findings), seeking to normalise epilepsy (complementary findings), and parents' reactions to epilepsy (complementary findings). The three remaining barriers were silent in nature, occurring in only one phase; parent overprotection, and CWE's level of seizure control, and CWE's attitudes towards their epilepsy (See Figure 10.4).

In total, parents perceived ten barriers to epilepsy-related communication. Five of these barriers were derived across both phases of the study; not wanting to cause CWE worry (convergent findings), discouraging CWE to dwell on epilepsy (convergent findings), seeking to normalise epilepsy (complementary findings), coming to terms with epilepsy (complementary findings), and parents' past experiences of epilepsy prior to CWE's diagnosis (complementary findings). The five remaining barriers for parents were silent in nature. These were; the invisibility of epilepsy, fear of misinforming CWE, discussing sensitive unpredictable issues, CWE's disposition, and portrayals of epilepsy in the media (See Figure 10.4).

The most prevalent barriers to epilepsy-related communication for CWE and parents were avoiding worry related to epilepsy, and seeking normalcy surrounding the condition. Across both phases of the study, CWE and their parents indicated that they would be unwilling to engage in epilepsy-related communication if they felt that such conversations may cause the other person worry or concern. However, quantitative findings revealed that, less epilepsy-related communication may result in greater epilepsy-related worry for CWE. These findings suggest that misconceptions may exist regarding what level of epilepsy-related communication CWE and parents perceive as worrisome and what level of communication may contribute to levels of worry. CWE and parents also indicated they may not talk about epilepsy together in order to maintain what they perceived as "normal" family life. Quantitative findings suggest, however, that open communication relating to epilepsy is linked to CWE reporting less need for normalcy surrounding their condition. Another barrier to epilepsy-related communication that emerged across both phases of the study was not talking about epilepsy in order to avoid activity restrictions. This finding relates to CWE's sense of autonomy and the threat that epilepsy-related communication may pose for their independence. Key issues of worry avoidance, seeking normalcy, and CWE autonomy and their implications for epilepsy-related communication are further discussed in sections 10.3.3, 10.3.4, and 10.3.5 of this chapter.

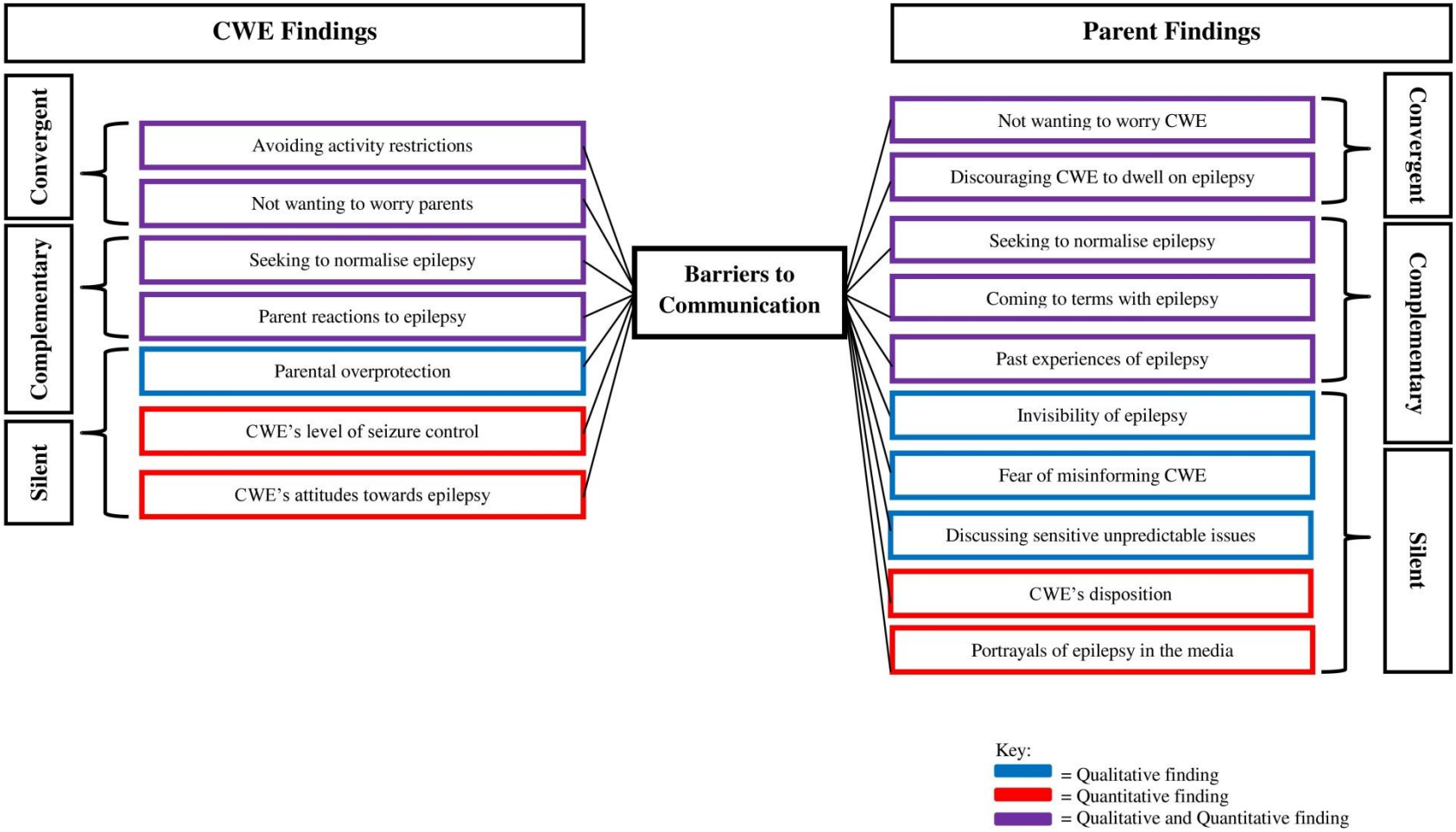


Figure 10.4: ***Barriers to Epilepsy-related Communication: Integrated Findings***

10.2.5 Enablers of Epilepsy-related Communication

Three enablers of epilepsy-related communication were identified by CWE in total. Two of these enablers were identified in both study phases and relayed convergent findings; parent knowledge of epilepsy and the availability/willingness of parents to engage in epilepsy-related communication. A final enabler in the form of CWE epilepsy-related knowledge emerged solely in the quantitative phase (See Figure 10.5).

Parents reported a greater number of perceived enablers to parent-child communication about epilepsy, identifying six in total. One enabler was viewed across both study phases; encouraging CWE autonomy. Findings relating to this enabler were convergent in nature. All remaining themes were silent in nature; pre-empting CWE concerns, the use of humour in interactions, greater CWE seizure control, parent attitudes towards epilepsy, and parent knowledge surrounding epilepsy (See Figure 10.5).

Integrated findings reveal an overarching theme of epilepsy-related knowledge enabling parent-child epilepsy-related communication. Though a greater level of knowledge relating to epilepsy has been pinpointed as a necessity for epilepsy-related discussions previously, this finding confirms that greater knowledge relating to epilepsy enhances more effective parent-child communication about the condition from both CWE and parent perspectives. Additionally, though solely from parents' perspectives, affording CWE a greater level of autonomy has been highlighted as a key enabler of epilepsy-related communication across both phases of the present study. Ensuring that CWE and parents are sufficiently informed about epilepsy, and allowing CWE a greater sense of autonomy, may represent measures that can be introduced via an effective family-based communication intervention seeking to enable parent-child communication about epilepsy. The issues of epilepsy-related knowledge and CWE autonomy are further discussed in sections 10.3.2 and 10.3.5 of this chapter.

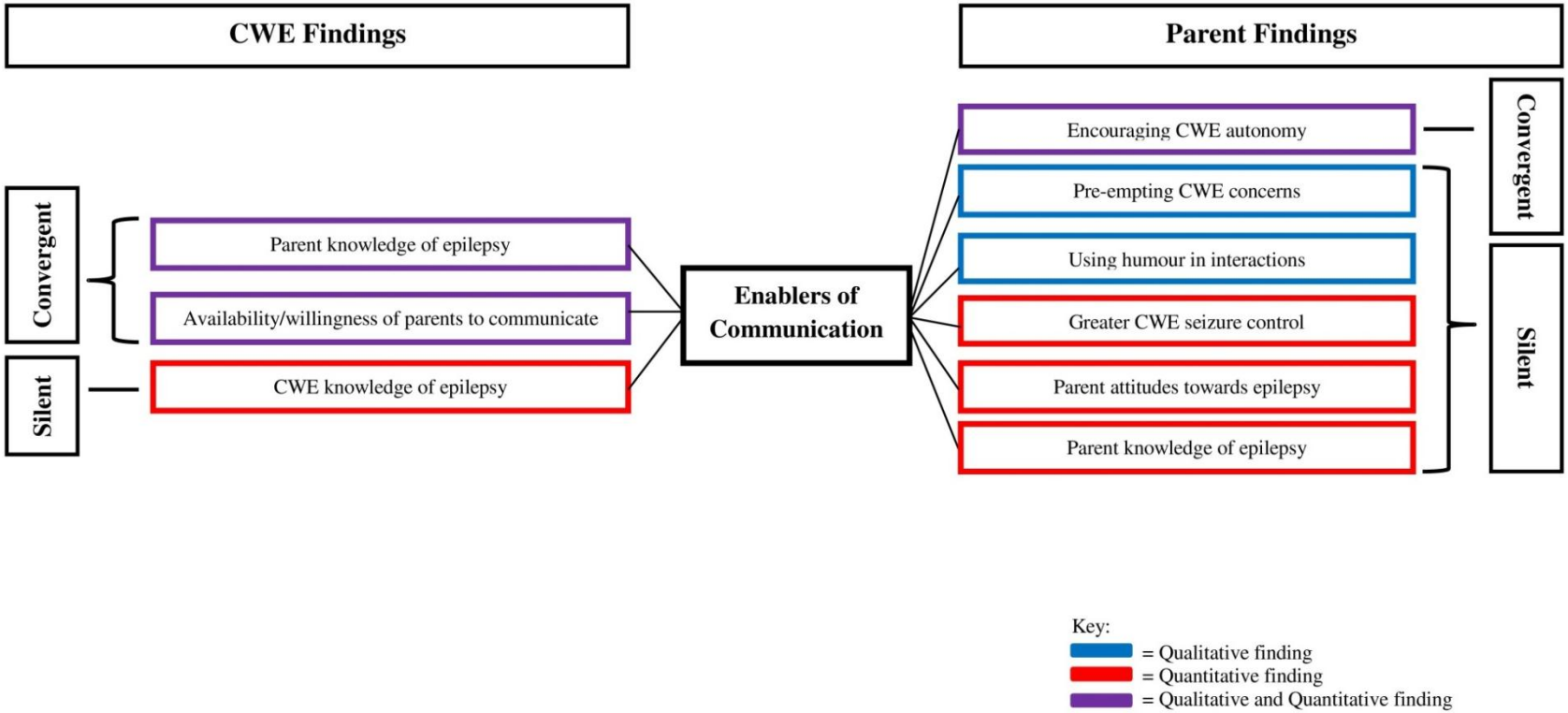


Figure 10.5: ***Enablers of Epilepsy-related Communication: Integrated Findings***

10.2.6 Consequences of Epilepsy-related Communication

The integrated findings revealed varying consequences (both positive and negative) of conversing about epilepsy for CWE and parents. All themes relating to these consequences were silent, only occurring in one phase of the study. Five consequences of epilepsy-related communication existed for CWE; a greater knowledge of epilepsy, being reminded of epilepsy-related restrictions, feeling happy, feeling brave, and feeling worried. Four consequences were identified for parents following communicating with CWE about epilepsy; feeling greater informed about epilepsy, feeling optimistic, feeling reassured, and feeling anxious (See Figure 10.6).

CWE and parents commonly felt greater-informed in relation to epilepsy following talking about the condition together. However, though the consequences of communicating about epilepsy were predominantly positive for CWE and parents, consequences such as feelings of worry and anxiety were also identified. These consequences support CWE's and parents' desire to avoid worry when engaging in dialogue about epilepsy. In the qualitative phase CWE also stated that epilepsy-related communication reminded them of epilepsy-related restrictions that may be imposed on them. Although the quantitative phase did not directly support this theme, avoiding activity restrictions emerged as a substantial barrier to communication for CWE across both study phases. This finding corroborates the potential connection between CWE's desire for autonomy and parent-child epilepsy-related communication.

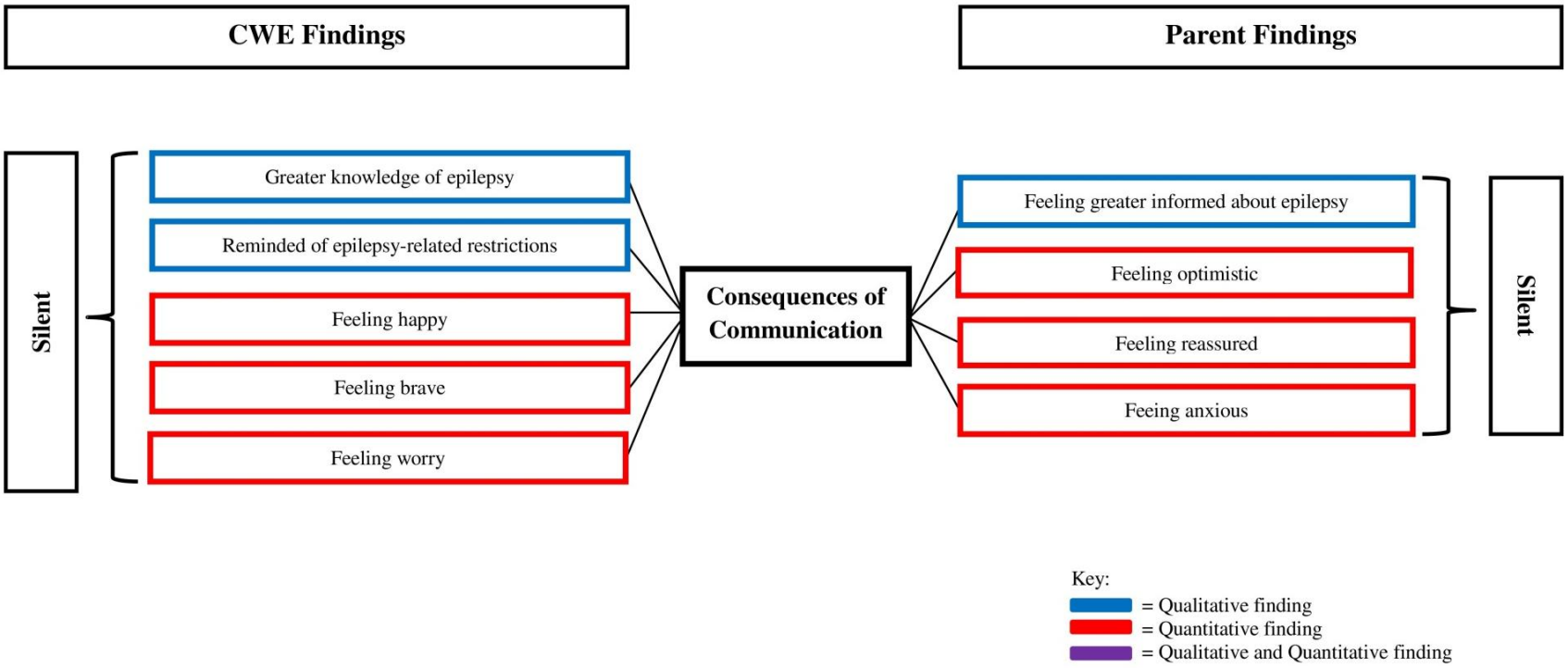


Figure 10.6: ***Consequences of Epilepsy-related Communication: Integrated Findings***

10.2.7 Epilepsy-related Communication and Psychosocial Wellbeing

The final category within which qualitative and quantitative findings were integrated was surrounding the relationships between epilepsy-related communication and psychosocial wellbeing. Associations uncovered relating to open parent-child communication and closed parent-child communication are outlined in Figure 10.7 and Figure 10.8 respectively.

Nine associations between open communication about epilepsy and CWE's psychosocial wellbeing were uncovered. Two of these associations were identified across both phases of the present study; positive illness attitudes (complementary findings), and greater perceived social support (complementary findings). The remaining seven associations were silent in nature. With regard to parent perspectives, seven associations were uncovered between open communication about epilepsy and parent psychosocial wellbeing. Three of these associations were seen across both study phases; positive responses to epilepsy (complementary findings), providing CWE with greater support (complementary findings), and greater encouragement of CWE autonomy (complementary findings). The remaining four associations were silent (See Figure 10.7).

Considering closed communication about epilepsy, thirteen associations between closed communication and CWE's psychosocial wellbeing were uncovered. All of these associations were silent in nature solely occurring in the quantitative phase. Ten associations were uncovered between closed communication and parent psychosocial wellbeing. Three of these associations were seen across both study phases; negative responses to epilepsy (complementary findings), greater perceive stigma (complementary findings), and providing CWE with less support (complementary findings). The remaining seven associations were silent (See Figure 10.8).

Findings from the present study suggest that open communication about epilepsy between parents and CWE is associated with positive psychosocial wellbeing amongst CWE and parents. However, conversely, emergent themes also suggest that closed communication about epilepsy is potentially linked with poorer psychosocial wellbeing amongst CWE and parents. Notwithstanding these conflicting findings, links between the communication approaches adopted by parents and CWE's attitudes towards their epilepsy were identified. The findings from this study suggest, for instance, that the CWE of parents adopting an open approach to epilepsy within the home may have more positive attitudes towards their epilepsy and therefore face fewer challenges in engaging in parent-child dialogue about epilepsy. This key finding of epilepsy-related attitudes and their implications for parent-child communication about epilepsy will be further discussed in section 10.3.6 of this chapter.

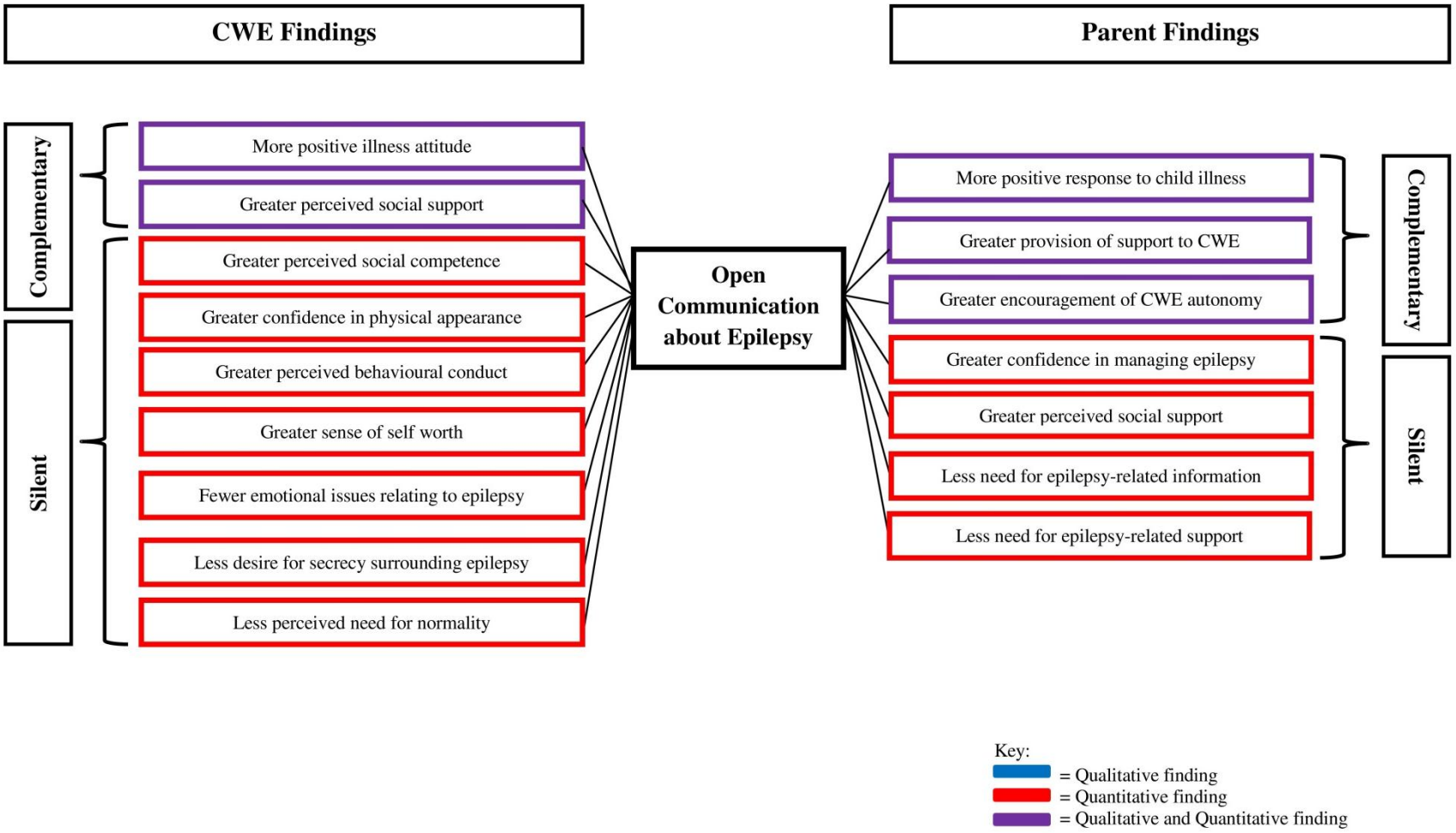


Figure 10.7: ***Open Epilepsy-related Communication and Psychosocial Wellbeing: Integrated Finding***

Figure 10.8: ***Closed Epilepsy-related Communication and Psychosocial Wellbeing: Integrated Findings***

10.2.8 Summary of the Integrated Findings

Both phases of this mixed-method study have identified novel findings relating to how CWE and parents communicate about epilepsy, and how epilepsy-related communication impacts upon psychosocial wellbeing. Themes integrated across both study phases provide weight to findings relating to the communication strategies, contexts, content, barriers, enablers and consequences of parent-child communication about epilepsy, and the relationships demonstrated with CWE and parent psychosocial wellbeing. Overall, this study has identified a number of the key findings associated with parent-child dialogue about epilepsy which are critically interpreted and discussed below.

10.3 Discussion of Key Findings of the Present Study

Integration of the qualitative and quantitative study phases has elucidated six key findings relating to the way in which CWE and their parents dialogue about epilepsy. These include; (1) the challenge that condition visibility presents for parent-child communication about epilepsy; (2) the positive impact of greater knowledge about epilepsy on parent-child communication; (3) the barrier that fear of causing worry presents for parent-child communication about epilepsy; (4) the role of communication in CWE and parents' quest for normalcy whilst living with epilepsy; (5) the issues that epilepsy-related communication presents for CWE's desire for autonomy; and (6) the impact of CWE's, parents', and the public's epilepsy-related attitudes on parent-child communication about the condition.

10.3.1 Talking about something that isn't there: The Challenge of Condition Visibility on Parent-Child Dialogue about Epilepsy

The concept of condition visibility and the challenge it presents for parent-child communication about epilepsy was a common core theme that was threaded throughout the present study's findings. Condition visibility, in the context of this study, refers to how detectable a chronic condition may be to others. For families of CWE, epilepsy may be a largely invisible condition within the home. In the absence of symptomatic reminders, such as seizures or epilepsy-related routines, CWE's epilepsy can become an "invisible" entity. It is recognised within the research literature that invisible conditions may present complications when tasked with talking about the condition, or disclosing the condition, to others external to the family unit (Joachim & Acorn, 2000a; Horan et al., 2009). According to the lens of the visibility framework developed by Joachim and Acorn (2000a), compared to people with visible conditions, people with invisible

conditions have greater choice to conceal and/or limit communication surrounding their condition. The decision to communicate about a chronic condition may therefore be a prominent concern for people with invisible conditions such as epilepsy.

Much of the research surrounding invisible conditions has been concerned with the presence of stigmatisation when choosing to talk about the condition with others (Joachim & Acorn, 2000b; Hoppe, 2010; Tröster, 1997). Though this research presents valuable insights into how people with epilepsy may communicate about epilepsy outside the family unit, epilepsy-related communication within the home is also of potentially particular relevance to CWE. The social worlds of CWE are smaller than adults living with epilepsy and illness-related communication most commonly occurs with family members, most prominently their parent(s). For the first time, the current study identifies evidence of the impact of condition visibility on epilepsy-specific communication between CWE and their parents.

This key finding of condition visibility conveyed by CWE and parents relates to the fact that parent-child communication surrounding epilepsy generally occurs during times of epilepsy-related events. Epilepsy-related events such as seizures, hospital appointments, changes in medication, and instances of needing to talk about epilepsy with others external to the family unit acted as catalysts for conversations relating to epilepsy between CWE and their parents. Notwithstanding this however, on the other hand, for families of CWE experiencing greater seizure control and fewer epilepsy-related events (i.e. with epilepsy becoming largely invisible) the opportunities to talk about the condition within the home were diminished.

These findings potentially suggest that condition visibility can either enable or impede parent-child communication about epilepsy. For instance, in the qualitative phase of this study parents stated that they experienced the invisibility of epilepsy as a barrier to effective parent-child communication about the epilepsy. Whereas, in the quantitative phase of this study parents relayed that greater seizure control (i.e. – fewer epilepsy-related events and hence greater invisibility of the condition) enabled them to engage in epilepsy-related communication with their child. Perhaps these findings suggest that there are different lens through which to interpret the concept of condition visibility; specifically related to the predictability of epilepsy related events. While findings suggest that predictable epilepsy-related events such as hospital appointments or daily medication routines may facilitate parent-child dialogue about epilepsy, on the contrary unpredictable events such as seizures may present more difficult and distressing situations for parent-child communication. These findings advance Joachim and Acorn's

(2000a) visibility framework by proposing that the predictability of visible illness-related events may impact upon individuals' decisions to communicate about a chronic condition.

Unpredictability and uncertainty are issues inherent in a diagnosis of childhood epilepsy (Oostrom, Schouten, Kruitwagen, Peters, & Jennekens-Schinkel, 2001). As the findings of this study demonstrate, seizures, in particular, can present a distressing and unpredictable event for both CWE to experience and their parents to witness. This is important because as Galletti, Rinna, and Acquafondata (1998) propose CWE's perceptions of their seizures can be guided by their parents' perceptions. Indeed, the findings of this present study suggest that parents experience challenges in discussing unpredictable episodes of epilepsy-visibility with their CWE. For instance, parents found it particularly difficult to respond to CWE queries about the typical appearance of their unpredictable seizures, in addition to, the uncertainty surrounding the potential of growing out of epilepsy. Contrastingly, structures and pre-determined epilepsy-related events such as hospital appointments and medication routines did not seem to present similar challenges. These findings suggest that CWE and parents may face difficulties in conversing about epilepsy during periods of visible, yet unpredictable, epilepsy-related events. One such period is at the time of initial epilepsy diagnosis.

The time period surrounding CWE's epilepsy diagnosis presents a crucial time for CWE and familial adjustment to the condition (for which parents are largely responsible) (Home & Kerirey, 1991; Cohen, 1999). During this time, epilepsy is a largely visible condition typically shrouded in numerous, possibly unpredictable, epilepsy-related events whilst CWE trial suitable antiepileptic medication (Marciani, Gotman, Andermann, & Olivier, 1985). Although the number of epilepsy-related events occurring at this time may present numerous opportunities to discuss epilepsy, parents in the present study highlighted the challenges they experience in conversing about epilepsy with CWE whilst they themselves come to terms with the epilepsy diagnosis. This difficulty, coupled with CWE's need for information at the time point of diagnosis, may result in a lack of epilepsy-related communication occurring at a pivotal time for CWE's adjustment to their condition.

Some of these findings may be explained by drawing on Rolland's (1984) *Psychosocial Typology of Chronic Illness* which posits differing developmental time phases of a chronic illness. According to this classification, the "crisis" phase begins at the first sign of symptomatology (i.e. – CWE's first seizure) and extends throughout the diagnosis period. This phase is characterised by high stress amongst family members, such as parents, in response to a

sudden and unpredictable illness which they are unprepared for. The findings of the present study provide congruence for this theory by demonstrating parents' difficulty in talking about epilepsy with CWE due to their own necessity to come to terms with the condition whilst learning to cope with CWE's seizures. The "crisis" phase during the onset of childhood epilepsy may be particularly acute due to the visibility of seizures and presence of unpredictable symptomatology.

To conclude, valuable information has been ascertained relating to the impact of condition visibility on CWE's and parents' decision to talk about epilepsy together. Given the level of condition visibility apparent at the time of an epilepsy diagnosis, and the opportunities for communication this raises, it is important to establish communication surrounding epilepsy from the outset of CWE's diagnosis. Engaging in parent-child communication about epilepsy-related events may help both CWE and parents to better cope with the stress that an epilepsy diagnosis presents. Creating a sense of comfort surrounding communication about unpredictable issues may result in positive psychosocial outcomes for CWE and their parents throughout the illness trajectory. Furthermore, ensuring that epilepsy may be openly discussed within the home, regardless of condition visibility or invisibility, should be advocated.

10.3.2 Greater Knowledge of Epilepsy Facilitates Parent-Child Communication about Epilepsy

Maintaining a high level of illness-related knowledge can give individuals with chronic illness a greater sense of control over their condition (Felton & Revenson, 1984). This is particularly true for people with epilepsy for whom epilepsy-specific knowledge has been demonstrated to impact positively on illness-related attitudes (Austin, Dunn, Perkins, & Shen, 2006), quality of life (Suurmeijer, Reuvekamp, & Aldenkamp, 2001), and social competence (Suurmeijer et al., 2001). Findings from the present study relay that greater levels of condition-related knowledge not only reflect greater social competence in environments external to the family unit but, for the first time, also reflect greater facilitation of condition-related communication within the home.

Epilepsy is a complex neurological condition that may prove difficult for CWE and parents to understand, particularly when learning about it initially. A combination of complex seizure terminology, prognoses, and aetiology contribute to the potential confusion surrounding epilepsy-related information. Though adults with epilepsy may actively search for epilepsy-related information via HCPs, support organisations, or the internet, the pathways for CWE to learn about their condition are largely grounded within the family unit. Parents of children living

with chronic illnesses often undertake the role of communication broker, providing easier-to-understand condition-related information for their child's comprehension (Young et al., 2003). The present study lends support to Young et al.'s (2003) study by confirming the role of parents as primary information-providers for CWE with regard to their epilepsy.

The positive influence of epilepsy-related knowledge on parent-child communication about the condition has been demonstrated throughout the present mixed-method study. Within the qualitative phase, CWE identified a greater level of parental epilepsy-related knowledge as an effective enabler of parent-child communication about the condition. Parents' fears of misinforming CWE due to a lack of knowledge relating to their epilepsy further highlight how a greater level of epilepsy-related knowledge may afford them greater confidence in discussing epilepsy with CWE. Within the quantitative phase, CWE who attributed more negative feelings towards parent-child communication indicated a greater need for epilepsy-related support, perhaps suggesting that their epilepsy-related queries were not adequately answered within their discussions with parents. Similarly, parents who adopted closed communication strategies in relation to epilepsy indicated that they were themselves in need of greater support, including epilepsy-related information. In order to comprehensively investigate the beneficial outcomes relating to CWE and parents feeling greater informed about epilepsy it is necessary to examine the epilepsy-related information pathways at play within families of CWE.

As evidenced by the present study and previous literature, CWE generally rely on their parents to support and guide them in learning about their condition (Hanai 1996; Hirfanoglu et al., 2009; Jantzen et al., 2009). The present study demonstrates how CWE often identify parents as non-judgemental listeners and sources of information with regard to their epilepsy. Although CWE are often present for hospital appointments relating to their epilepsy, parents and doctors often take leading roles with regard to diagnostic and treatment information during these engagements. A dearth of literature exists surrounding the role of CWE during HCP engagements. Research investigating doctor-parent-child triadic communication during the hospital appointments of children with other chronic illnesses outlines that children are often overlooked as effective communicators about their own condition during these engagements (Tates & Meeuwesen, 2001). However, the conversational contribution of children has been shown to grow over time (Meeuwesen & Kaptein, 1996). Indeed, findings of the present study illustrate how CWE turn to their parents for information following HCP engagements, communicating about epilepsy before and following hospital appointments. Relaying epilepsy-

related information to CWE was not without its challenges however, particularly at the point of diagnosis during which parents were learning about their child's epilepsy for the first time.

A diagnosis of childhood epilepsy can represent a significant "stressor" impinging on the family system of CWE. Bronfenbrenner's (1979) social-ecological systems theory posits that family systems fluctuate over time, in response to familial highs and lows (such as stressors). Communication with children with chronic illnesses has been previously identified as a considerable source of stress for parents (Barakat, Patterson, Tarazi, & Ely, 2007). Research seeking to apply social-ecological systems theory to families of children with chronic illness has highlighted the impact that evolving knowledge relating to the condition may have for chronically-ill children and their parents' adaptation and communication (Kazak, 1989). The findings of the present study builds on this research to support communication within families of CWE, as the qualitative findings have shown that parents feel more comfortable communicating about epilepsy after they have effectively learned about and come to terms with CWE's diagnosis. Findings relayed within the quantitative phase substantiate this evidence by demonstrating associations between parents needing less condition-related information and parents adopting open epilepsy-related communication strategies.

Despite representing a key source of information for CWE, findings here reveal that many parents feel under-informed in relation to their child's epilepsy diagnosis. Parents felt unsure of where to access reliable information and/or found epilepsy-related information complex and difficult to understand. This impacted on parents' ability to explain the condition to CWE and presented difficulties for engaging in parent-child dialogue about epilepsy. Parents of CWE often turn to HCPs as their first point of inquiry at the time of an epilepsy diagnosis for their child. Discussions with HCPs may inform the level of knowledge parents have about their CWE's specific form of epilepsy and, consequently, their ability to relay this information to CWE. Parents who lack information feel ill-equipped to answer CWE's epilepsy-related questions resulting in CWE feeling under-informed about their epilepsy. A greater level of parental epilepsy-related knowledge has been previously linked to parents placing fewer restrictions on CWE (Hirfanoglu et al., 2009); however, no further potentially positive associations have been examined within the research literature. The present study has identified valuable information on the benefits of parental epilepsy-related knowledge in facilitating open communication about epilepsy within the home. This information is important given the demonstrated benefits of open epilepsy-related communication for CWE's and parents' psychosocial wellbeing.

HCPs are often the primary source of epilepsy-related information for CWE and their parents at the time-point of diagnosis; however, this study suggests that parents also learn about CWE's epilepsy from discussions with CWE about their condition. Indeed, parents within the qualitative study phase relayed feeling under-informed about CWE's specific type of epilepsy and/or seizures', indicating that generic information was more accessible however information specific to their child's experience was sometimes difficult to obtain. Findings suggest that a bi-directional positive relationship exists between epilepsy-related knowledge and parent-child communication about epilepsy. For instance on the one hand a greater level of epilepsy-related knowledge can potentially encourage enhanced engagement in dialogue and on the other hand engaging in dialogue promotes a greater level of knowledge surrounding epilepsy. HCPs should not only endeavour to provide parents of CWE with tailored epilepsy-related information, but also relay the importance of establishing open communication about epilepsy with CWE. The present study presents a shift in healthcare communication to within the family context; parents should be cognisant of the impact of their epilepsy-related discussions, or lack thereof, with CWE.

In summary, the findings of the present study highlight the importance of parental roles and behaviours in the facilitation of epilepsy-related dialogue within the home. Novel evidence is presented on the benefit of knowledge about epilepsy in encouraging parent-child communication about the condition. The level of knowledge parents have in relation to their child's epilepsy may inform CWE's level of epilepsy-related knowledge. The information discovered here, for the first time, provides a valuable contribution to knowledge and suggests that communication interventions for families of CWE should include educational components when aiming to open channels of communication in relation to epilepsy between CWE and parents.

10.3.3 Fear of Causing Worry Impedes Parent-Child Communication about Epilepsy

Fear that talking about epilepsy would give rise to one another's epilepsy-related concerns was central to CWE's and parents' communication about epilepsy within the home. Indeed, worry relating to epilepsy is not uncommon. The unpredictability of epilepsy gives rise to a greater level of concern and worry amongst CWE and their parents when compared to children and parents living without epilepsy (Williams et al., 2003). CWE and parents worry about issues such as; seizures, antiepileptic medication, the cause of epilepsy, seizure-related injury risks, rick of mental health problems, and the social prognosis of CWE's epilepsy (Austin et al.,

1998). Furthermore, greater CWE and parent worry in relation to epilepsy has been previously linked to a more negative epilepsy-related attitude, greater perceived epilepsy-related stigma, and lower levels of self-efficacy for epilepsy management (Austin et al., 2004). For this reason, worry is now known to have a key association with quality of life in individuals with epilepsy (Loring, Meador, & Lee, 2004). Consequently, how CWE and their parents seek to actively cope with epilepsy-related worries may influence their overall quality of life. Prior to the conduct of the present study, however, the potential transmission of epilepsy-related worry between CWE and their parents via conversations about the condition has remained unexamined.

Research in the area of chronic illness and parenting has found that parents of children with chronic illnesses often live with constant worry in relation to their child's condition (Coffey, 2006). However, to the author's knowledge, no studies have sought to describe how parents of chronically-ill children and their children may communicate about potentially worrying condition-related information. Attachment theory proposes that children's level of worry is influenced by the way in which they are attached to their parents (Bowlby, 1973). Indeed, parental attachment and rearing behaviours have been previously linked to worry in children (Muris, Meesters, Merckelbach, & Hülsenbeck, 2000). A fundamental aspect missing from these propositions, however, is precisely how parents and children interact about worrisome issues. This area is of particular interest in the lives of CWE and their parents given the heightened level of worry recorded within this population. Valuable information has arisen from the present study regarding how worry may impact upon parent-child interactions about epilepsy specifically.

An awareness of the potential to evoke worry in one another was a primary barrier to communication reported by CWE and parents, across both phases of the study. CWE and parents feared relaying potentially worrying information to one another by way of epilepsy-related conversations. Specific information has been elucidated regarding the precise epilepsy-related areas in which CWE and parents fear that their communication may cause worry. For example, CWE in the qualitative phase relayed that they did not wish to speak to parents about seizure-like symptoms (e.g. – a headache) for fear of causing them unnecessary concern. Similarly, parents were sometimes restrictive of the information they afforded CWE in relation to antiepileptic medication side effects, for fear of causing them undue worry. Baker et al. (1999) alluded to how epilepsy-related worry, or related constructs such as stigma perceptions, may arise as a consequence of experiencing others' worry in relation to epilepsy. This

consequence is at the core of CWE's and parents' concerns relating to epilepsy-related communication.

Despite parents' fear of relaying epilepsy-related worries to CWE, findings uncovered in the quantitative phase of the present study reveal that closed communication is actually associated with greater epilepsy-related worry and concern for CWE. Therefore, although parents may seek to protect CWE from worrisome information by not engaging in epilepsy-related dialogue with them, they may actually exacerbate CWE's epilepsy-related concern by doing so. Social support remains a key alleviator of worry for the chronically-ill (Kaplan & Hartwell, 1987). Increased parent-child communication and caring have been associated with adolescent wellbeing and emotional health by way of alleviating any worries children may have (Ackard, Neumark-Sztainer, Story, & Perry, 2006). Parent-child conversations about epilepsy may provide important opportunities for CWE to voice epilepsy-related concerns in an environment that they consider accepting. Increased levels of communication may therefore aid in reducing their level of worry. Similarly, by virtue of greater epilepsy-related knowledge being identified as a positive consequence of parent-child communication about epilepsy for parents in the present study, increased levels of communication may also reduce parental concerns relating to epilepsy.

Though CWE's cognisance of parental worry in relation to epilepsy has been documented previously (Moffat et al., 2009), parental worry behaving as a barrier to CWE engaging in parent-child dialogue is a novel finding of the present study. This finding suggests that parents should be cognisant of the attitudes and feedback they convey to CWE during epilepsy-related interactions. Parents behaving in a worried or over-reactionary manner may discourage CWE from initiating dialogue about epilepsy with them in the future, encouraging the adoption of closed communication strategies surrounding the condition within the home. Similarly, fear of causing worry was at the forefront of many parents' communication-related concerns across both study phases. The findings of the present study not only highlight the issue of parent worry but also identify parents' fear of causing CWE similar worries in relation to their condition via epilepsy-related discussions with them.

The present mixed-method study conveys important novel findings relating to CWE and parent worry and its impact upon epilepsy-related dialogue within the home. A disconnect has been found between CWE's and parents' perceptions of their conversations causing worry and the advantageous effect of such discussions to promote emotional wellbeing and alleviate concern. Parents should be made aware of the potential worry caused by not conversing with CWE about

their condition. This advice and guidance relating to the importance of open communication in eradicating epilepsy-related worry could form an integral part of a family-based communication intervention for families of CWE.

10.3.4 Parent-Child Communication about Epilepsy places Families' Quest for Normalcy at Risk

The task of seeking what was perceived as "normality" when living with childhood epilepsy was important for CWE and parents in the present study. Helping CWE to avoid feelings of differentness as a consequence of their epilepsy was a key reason influencing both CWE's and parents' decisions to not engage in a dialogue about the condition or to limit their epilepsy-related discussions within the home. Indeed, within the qualitative phase of this study, CWE reported that epilepsy-related communication impeded their sense of normalcy by making them feel different and reminded them of the restrictions their epilepsy imposes on their lives. As epilepsy-related communication was typically viewed as a task that families of children without epilepsy do not have to engage in, talking about epilepsy was therefore thought to infringe upon "normal" family life.

The issue of normalcy seeking is well-documented amongst children living with chronic illness (Sartain et al., 2000; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980). Within their research investigating communication in families of children with chronic illnesses, Branstetter, Domian, Williams, Graff, and Piamjariyakul (2008) deduce that the struggle for normalcy experienced by these families was a two-step communicative process involving; 1) problem-solving communication, and 2) the use of creative strategies to ensure that family life continued as normal in light of the presenting condition. Interestingly, however, the communication processes described by Branstetter et al. (2008) rarely involved communication with the chronically-ill child, instead describing a collaborative attempt from family members to instil a sense of normalcy within the family context. The findings of the present study support this research by revealing that parents engaged in less epilepsy-related dialogue with CWE due to this consistent, and silent, strive for normalcy.

So why is this strive for normalcy in everyday family life a largely silent process for CWE and their parents? The normalisation process is undertaken by families of chronically-ill children in order to deconstruct the "disease" label attributed to the child and emphasise their normality (Anderson, 1981). However, it is important to also assess how children construct their own sense of "normality". The quest to appear "normal" and to "fit-in" is an integral component of

adolescence. On investigating the issue of normalcy amongst CWE, Elliott et al. (2005) proposed that CWE viewed their seizures as a pivotal barrier to them leading what they perceived as a "normal" life. Not only this, but the stigma and embarrassment associated with having a seizure caused CWE to view themselves as different to their peers. Joachim and Acorn (2000b) argue for the importance of viewing children with chronic illness as agents in the creation of their own social contexts. Assuming this perspective, CWE may actively formalize their own sense of normalcy surrounding how their condition is viewed by others. Although normalcy-seeking behaviours, such as concealing a condition from others, have been demonstrated in environments external to the family environment (Scambler, 2009), the present study outlines novel evidence regarding the impact of normalcy-seeking on parent-child communication about epilepsy.

Within the present study, CWE and their parents viewed parent-child discussions about epilepsy as a threat to their desired sense of normalcy. Therefore, even when CWE were not experiencing frequent seizures, avoiding feelings of differentness and promoting normalcy was pinpointed as a key reason for them not to engage in parent-child dialogue about epilepsy. From a parent perspective, parents felt that by discussing epilepsy they may invoke feelings of differentness for CWE, highlighting their "different" status, for example, in comparison to siblings. By seeking normalcy for CWE, many parents avoided talking about epilepsy during times when epilepsy was not apparent in the lives of CWE (e.g. – periods of greater seizure control) in order to lessen feelings of differentness and/or burden.

These findings relating to normalcy suggest that certain epilepsy-related communication topics caused CWE to feel different in comparison to children living without epilepsy. CWE's perceptions of epilepsy-related communication as a reminder of activity restrictions, coupled with activity restrictions acting as a barrier to effective parent-child communication about epilepsy, advances an argument for communication about activity restrictions impeding CWE's sense of normalcy. Parents of CWE are known to place a greater number of restrictions on CWE when compared to parents of non-chronically-ill children (Carpay et al., 1997). This is often in response to HCPs advice regarding the risk of seizure-related injuries (Thompson & Oxley, 1993). Whilst epilepsy-related activity restrictions are known to impact upon CWE's sense of normalcy in their social world, this has largely been related to social participation external to the family unit (Meijer et al., 2000). The present findings highlight the influence of parent-child epilepsy-related communication, particularly in relation to activity restrictions, on CWE's sense of normalcy within the family context.

Though not talking about epilepsy was thought to encourage a sense of normality for CWE, the quantitative phase of the present study revealed that, conversely, open communication strategies and a greater level of epilepsy-related communication were associated with less perceived need for normalcy amongst CWE. This suggests that any silence maintained surrounding epilepsy within the family actually results in poorer outcomes for CWE; resulting in them feeling greater levels of "differentness". As with the issue of epilepsy-related worry, fundamental misconceptions exist regarding what level of epilepsy-related communication may invoke feelings of differentness amongst CWE. Parents should endeavour to open channels of communication about epilepsy with CWE in order to ensure that silence doesn't encircle the condition, as this silence may contribute to CWE's perceived "different" status.

The present study reveals novel information relating to how the issue of normalcy may impact upon families living with childhood epilepsy and, particularly, parent-child engagements about epilepsy. Desire for normalcy is distinguished as a key finding in the present study given its influence on the openness and level of parent-child epilepsy-related communication. Parents of CWE may benefit from a family-based communication intervention that provides guidance on effectively creating a sense of normality surrounding epilepsy within the home. The unique evidence identified here suggests that interventions should focus on encouraging adequate levels of communication relating to CWE's epilepsy-related activity restrictions. These measures could not only reinforce a sense of normalcy surrounding epilepsy, but could also reinforce normalcy surrounding parent-child epilepsy-related discussions; resulting in a greater level of parent-child communication about epilepsy and subsequently greater psychosocial outcomes for CWE and their parents.

10.3.5 CWE Desire for Autonomy and Parental Overprotection Impacts on Parent-child Communication

A key finding of the present study is the way in which CWE's desire for autonomy impacts on CWE's and parents' epilepsy-related communication within the home. Issues of autonomy were particularly apparent for older CWE in both phases of the present study as they were more likely to discuss independence-related matters in light of their epilepsy. For example, growing out of epilepsy, driving, and career prospects were topics referred to by CWE and parents within the qualitative phase of the present study. Perhaps these findings are not surprising considering that the development of autonomy is considered a fundamental element of adolescence (Zimmer-Gembeck & Collins, 2003). Indeed, autonomy development for adolescents with epilepsy can be particularly challenging with the condition impacting negatively on their independence due to

epilepsy-related activity restrictions and the possible over-protective behaviour of parents (McEwan et al., 2004). This study, however, has identified novel evidence that communicating about autonomy issues in early adulthood is a sensitive topic for CWE and parents to discuss. Original evidence relating to the autonomy-related issues that CWE and parents discuss was revealed within the qualitative component of the present study. Issues ranging from CWE growing out of their epilepsy condition, activity restrictions imposed on CWE as a result of their epilepsy, and epilepsy-related challenges yet to arise in the lives of CWE comprise a number of the sensitive autonomy-related topics of conversation typically engaged in. Findings of the present study suggest that parents faced particular difficulty in discussing sensitive autonomy-related issues with CWE. Reasons for this difficulty may be two-fold; parents' inability to provide CWE with certainty surrounding their condition due to its unpredictability, and parents desire to protect CWE. Though the challenge that epilepsy's unpredictable nature may cause for condition-related communication within the family has been commented upon previously, parents' role as protector of CWE (and the impact this may have on how they communicate with CWE) is a another novel finding of the present study.

These findings of the present study do, however, lend support to previous research on family stress, coping, and adaptation (Hill, 1958; McCubbin & Patterson, 1983) which report that parents of chronically-ill children tend to adopt a protective role with regard to their child's condition. Heightened levels of anxiety, typically reported in CWE parent populations, may extend this protective behaviour to overprotection. Parental overprotection is characterised by an excessive concern over the child's health (Thomasgard, Shonkoff, Metz, & Edelbrock, 1995), and has been documented previously amongst parents of CWE (Jantzen et al., 2009; McEwan et al., 2004). Parental overprotection was viewed by CWE in the present study as a barrier to talking about epilepsy with their parents. Overprotective behaviours, as categorised by CWE, were conveyed via heightened levels of supervision and vigilance. In their seminal research, Green and Solnit (1964) proposed the *Vulnerable Child Syndrome* framework. This framework suggests that heightened levels of anxiety amongst parents in relation to their child's health, characterised in the present study as overprotection, may result in disturbances in parent-child interactions. Novel findings uncovered in the present study demonstrate congruence with this framework, identifying challenges CWE and parents face in light of sensitive discussions relating to CWE's autonomy.

Conversations relating to autonomy are a particularly pertinent finding of the present study given the health and safety implications of not talking about epilepsy for CWE. Within both

phases of the present study CWE reported not discussing epilepsy-related matters with their parents to avoid them restricting their social participation in activities. Older CWE seek the same autonomy as non-chronically ill children (Wagner & Smith, 2006); yet face additional challenges in doing so due to higher rates of parental overprotection and hyper-vigilance (another barrier to communication reported within the present findings) (Hirfanoglu et al., 2009; Jantzen et al., 2009; McEwan et al., 2004). Indeed, the quantitative findings of the present study reveal that CWE attribute fewer positive feelings to parent-child communication about epilepsy as they get older. The potential for activity restrictions to act as a barrier to parent-child epilepsy-related communication may present a significant health and safety risk to CWE, for example, if choosing to not disclose seizures to their parents.

Despite the challenge that conversing about autonomy issues presented for CWE and their parents, encouraging autonomy was also an effective mechanism in facilitating epilepsy-related communication. Although parents pinpointed conversations relating to CWE's autonomy as a potential barrier to talking about epilepsy (for example, when faced with discussing growing out of epilepsy or challenges yet to arise), parents also relayed how affording CWE greater autonomy aided them in facilitating a greater level of communication about epilepsy within the home. This suggests that measures encouraging parents to feel comfortable when discussing CWE's autonomy may facilitate a greater level of open parent-child communication about epilepsy within the family context. Indeed, findings from the quantitative phase of the present study indicate that greater parental encouragement of CWE's independence is associated with a greater level of epilepsy-related communication whereas affording CWE less autonomy is associated with CWE feeling negative emotions around epilepsy-related discussions. Given these benefits to CWE's psychosocial wellbeing it is important to examine how sensitive issues related to autonomy may be spoken about with ease by CWE and parents.

Within their research examining the impact of family connectedness, Ackard et al. (2006) suggest that parents may wish to practice conversing with their child about sensitive topics without lending judgement until explicitly asked. Following such conversations, a solution may be arrived at in a collaborative fashion. This strategy could promote CWE's willingness to engage in communication and allow them to understand parents views (Ackard et al., 2006). By arming parents with adequate information relating to future challenges yet to arise for CWE, such as the possibility of them growing out of epilepsy, and providing them with guidance relating to how to broach these topics with CWE, such as collaborative decision-making techniques, parents may feel better equipped to handle sensitive conversations with CWE.

In summary, talking about possible infringements that epilepsy may present on CWE's desire for autonomy was a challenging process for CWE and their parents. Epilepsy-related autonomy and overprotection issues sometimes led to a lack of communication surrounding epilepsy within the home. Notwithstanding this, the present study demonstrates the beneficial impact of affording CWE a greater level of autonomy in facilitating open communication about epilepsy. The promotion of CWE autonomy may therefore represent a key process for inclusion within an effective family-based communication intervention for families of CWE.

10.3.6 The Impact of Epilepsy-related Attitudes on Parent-Child Communication

A final pivotal finding of the present mixed-method study was the link demonstrated between epilepsy-related attitudes and the way that CWE and their parents choose to communicate about epilepsy. Qualitative and quantitative findings relay that, for CWE and their parents, open and supportive communication surrounding epilepsy is associated with a more positive epilepsy-related attitude, whereas closed communication is attributed to holding negative attitudes towards epilepsy.

Previous research has illustrated the beneficial impact of positive epilepsy-related attitudes on emotional and behavioural outcomes in CWE (Austin et al., 2006). Indeed, illness-related attitudes are reported as a strong indicator of child adjustment to chronic illness. This is a particularly important indicator in children living with a chronic illness with an attached stigma (Austin & Huberty, 1993). CWE who perceive their condition in a more negative light and view themselves as different to their non-chronically ill peers tend to withdraw from social interactions and become isolated (Lefebvre, 1983; Austin & Huberty, 1993). Epilepsy-related attitudes have therefore been demonstrated to hold strong implications for social engagements external to the family context. The present study brings to light, for the first time, the impact that epilepsy-related attitudes may have on CWE and parents' decisions to engage in dialogue within the family context.

Opportunities for CWE and parents to talk about epilepsy together may be of crucial importance to coping with the condition on a day-to-day basis. Furthermore, the present research suggests that epilepsy-related conversations occurring at a parent-child level may be essential for the development of positive epilepsy-related attitudes in both CWE and their parents, and vice versa. The pathways via which CWE and their parents develop attitudes relating to epilepsy are of particular interest in light of the present findings. CWE, parent, and public attitudes may all play a role in facilitating greater epilepsy-related communication between CWE and parents.

Research investigating adjustment to epilepsy has found that CWE may develop perceptions of their condition according to how those surrounding them perceive epilepsy (Baker et al., 1999). CWE, particularly adolescent CWE, typically harbour concerns relating to peer-acceptance and normalcy (Richardson & Friedman, 1974). Seizures in the company of peers are therefore a significant concern of some CWE. The present findings suggest that CWE seek to engage in parent-child dialogue about the manifestation of their seizures in other to learn how their condition may be perceived within their social world. Parents' behaviours during sensitive condition-related discussions regarding public attitudes towards epilepsy can play a lasting impact in terms of child psychosocial outcomes (Ziegler et al., 2000). As CWE's primary source of information and support, it is fundamental for parents to be cognisant of the attitudes conveyed during such engagements with CWE. The attitudes CWE choose to harbour in relation to their condition may dictate how epilepsy is spoken about within the home.

Given the influential position parents hold with regard to guiding their child's epilepsy-related attitudes, it is important to ascertain how parents' attitudes may also be developed. Family Stress Theory (Patterson, 1988) argues that if parents' perceptions of a stressor on the family (in this case, their child's epilepsy condition) are primarily negative, this may result in maladaptation to the illness and parents' perceiving greater stress on the family unit. On the other hand, if parents' perceptions of their child's condition are primarily positive this will result in enhanced coping for the family and successful adaptation to the condition. The novel findings of this present study provide support for this theory, explicating that positive epilepsy-related attitudes amongst parents of CWE are associated with open communication (an indicator of positive family functioning) and negative epilepsy-related attitudes are linked with the contrary.

Though Family Stress Theory highlights the development of perceptions at the beginning of the illness trajectory, public perceptions of epilepsy can also play a role in CWE's and parents' attitude formation. Considering the impact of public attitudes relating to epilepsy on how CWE and parents talk about the condition, public epilepsy-related attitudes were conveyed as a common topic of parent-child communication. Portrayals of epilepsy within the media and past experiences of epilepsy were also highlighted by parents as key barriers to their epilepsy-related communication with CWE. Epilepsy has a well-documented association with stigma in the public eye (Morrell, 2002). Though the number of educational-focused campaigns seeking to raise awareness about epilepsy has risen starkly in the past decade (Price, Kobau, Buelow, Austin, & Lowenberg, 2015), misconceptions and misinformation still exist within the public domain. Given the implications of public epilepsy-related attitudes for CWE's and parents'

dialogue relating to epilepsy, the findings of the present study add weight to an argument proposed by Jacoby, Gorry, Gamble, and Baker (2004) suggesting that public campaigns should seek to target attitudinal shifts rather than improvements in knowledge. By promoting more positive attitudes towards epilepsy in the public eye, a greater level of open communication relating to epilepsy may be facilitated within the home.

Considering the findings gathered across this mixed-method study pertaining to epilepsy-related attitudes and their implications for epilepsy-related communication, attitudinal development in CWE and their parents may be linked with talking about epilepsy. Pioneering evidence reported here for the first time demonstrates that positive epilepsy-related attitudes encourage a greater and more open level of parent-child communication about epilepsy. Furthermore, the present research suggests that a collaborative effort of positive CWE, parent, and public attitudes surrounding epilepsy may enable CWE and parents to discuss epilepsy more effectively. In this way, the eradication of stigma external to the family environment could have beneficial impacts on day-to-day communication within families of CWE.

10.4 Conclusions of the Integrative Discussion

The integrated findings have highlighted the themes elucidated from both the qualitative and quantitative phases of the present mixed-method study with regard to; communication strategies, communication contexts, communication contents, communication barriers and enablers, communication consequences, and associations between communication and psychosocial wellbeing identified by CWE and parents when talking about epilepsy within the home. Key findings such as; the challenge that condition visibility presents for parent-child communication about epilepsy, the positive impact of greater knowledge about epilepsy on parent-child communication about epilepsy, the barrier that fear of causing worry presents for parent-child communication about epilepsy, the role of communication in CWE and parents' quest for normalcy whilst living with epilepsy, the issues that epilepsy-related communication presents for CWE's desire for autonomy, and the role of CWE's, parents', and public attitudes relating to epilepsy in facilitating parent-child communication about the condition have been critically discussed according to their specific impact and implications for parent-child dialogue about epilepsy. The overarching implications of the present study, along with this study's original contribution, will be explicated in the following chapter.

Chapter 11: Conclusions

11.0 Introduction

This chapter presents the conclusions of the present research study. The original contribution of this research will be elucidated. Following this the strengths and limitations of the mixed method study will be examined. The implications of this research for clinical practice, future research, education, and policy will be outlined. Finally, this chapter will conclude with a summation of the present research.

11.1 Original Contribution of the Present Study

This study's contribution is made through providing new knowledge relating to parent-child dialogue about childhood epilepsy from both a parent, and CWE perspective and the relationship between these dialogue practices and the psychosocial wellbeing of CWE and parents. The first phase of this study has uncovered original information previously undocumented within the research literature pertaining to the ways in which CWE and parents choose to talk, or not talk, about epilepsy with each other. Specifically, novel information regarding the approaches taken by CWE and parents to communicate about epilepsy, the challenges they face in doing so, and the factors they deem helpful in facilitating these conversations have been elucidated. The second phase of this study identified a number of relationships between parent-child dialogue about epilepsy and CWE's and parents' psychosocial wellbeing. The level of discussion CWE and parents engage in, and the type of communication undertaken, has been demonstrated to be associated with stigma perceptions, illness attitudes, self-perception, health-related quality of life, perceived social support, and need for support in relation to CWE's condition. To the author's knowledge, no previous research has utilised mixed methodology to uncover the experiences of CWE and their parents when choosing to engage in dialogue, or not, about epilepsy and epilepsy-related issues. Through the qualitative and quantitative phases, issues such as seeking normalcy and avoiding worry have been uncovered as some of the potential barriers to parent-child conversations about epilepsy. Other factors, such as parents having knowledge about their CWE's epilepsy and encouraging CWE autonomy with regard to their epilepsy have emerged as positive facilitators of parent-child communication about the condition. As this study is exploratory in nature, it is hoped that the integrative findings contribute to knowledge by providing baseline information for the design of an effective family based communication intervention for families living with epilepsy. A breakdown of the present study's original contribution is detailed in table 11.1.

Table 11.1: ***Original Contribution of the Present Study***

	Supported	**Developed**	**New**
Theoretical Knowledge	*Provides theoretical support for:* • Family Stress Theory (McCubbin & Patterson, 1983) • Rolland's Psychosocial Typology of Illness (Rolland, 1984) • Visibility Framework (Joachim & Acorn, 2000a)	*Develops further knowledge relating to:* • Family Stress Theory (McCubbin & Patterson, 1983) • Rolland's Psychosocial Typology of Illness (Rolland, 1984) • Visibility Framework (Joachim & Acorn, 2000a)	
Empirical Evidence	*Supports existing empirical evidence relating to:* • Parent-child communication in the context of paediatric chronic illness (for example, diabetes and asthma) • Normalcy seeking behaviours in families living with childhood chronic illness • Communication surrounding invisible conditions (i.e., - chronic conditions not always identifiable to others)	*Develops upon empirical evidence by:* • Advancing research relating to family functioning in the context of epilepsy • Further highlighting how epilepsy's unique characteristics (i.e. – invisibility and unpredictability) result in communicative challenges	*Creates new empirical evidence relating to:* • Communication strategies employed by CWE and parents • Contextual factors impeding and encouraging epilepsy-related communication within the home • Specific barriers and enablers of epilepsy-related communication identified by CWE and parents • The impact of epilepsy-related discussions on the psychosocial wellbeing of CWE and parents
Methodological Approaches	*Supports methodological approaches employing:* • The use of mixed-methods in healthcare research • The use of a sequential exploratory design in healthcare research	*Further develops methodological approaches by:* • Directly accessing the voice of the child to elucidate their lived experiences from their perspectives rather than parent proxy reports • Using creative methods to establish rapport with child participants in qualitative interviews	*Contributes new methodological approaches via:* • The design of a new measure examining parent-child communication about epilepsy for use with CWE and parents of CWE

	Supported	Developed	New
Research Context	*Supports research in following contexts:* • Research investigating parent-child relationships and communicative behaviours • Research investigating quality of life issues amongst CWE and their parents	*Further develops research in the following contexts:* • Research investigating family functioning in families living with childhood chronic illnesses, with a particular focus on childhood epilepsy	*Unique context of the present research:* • Pioneering research in the context of families living with childhood epilepsy in Ireland
Practical Implications	*Supports practical implications for:* • The need for an epilepsy-awareness campaign focusing on the visibility of epilepsy in society	*Further develops practical implications for:* • The role of HCPs in effectively communicating chronic illness diagnoses to families of CWE	*Following unique practical implications:* • Advocates for the provision of specific, tailored and age-appropriate epilepsy-related knowledge for CWE and parents of CWE • Valuable novel information and suggestions elucidated for the development of a family-based communication intervention for families of CWE • Findings of the present study will contribute to the National Epilepsy Care Programme in Ireland

The present study's original contribution to research has been examined according to the following areas; theoretical knowledge, empirical evidence, methodological approach, research context and practical implications.

Regarding the present study's contribution to theoretical knowledge, this research provides support for a number of theories within family communication research. Elements of Family Stress Theory (McCubbin & Patterson, 1983) and Rolland's Psychosocial Typology of Illness (1984) have been demonstrated via evidence relating to the challenges CWE and parents face in communication about epilepsy at the "crisis" time-point of CWE's diagnosis. Specifically, the communication difficulties reported by parents when coming to terms with a diagnosis of

epilepsy for their child highlight the fluctuations in parent-child interactions in the presence of a family stressor. Another framework that the present study's findings both support and develop further is Joachim and Acorn's (2000a) Visibility Framework. The present findings extend evidence relating to the impact of condition visibility on communication external to the family unit to include communication within the family unit. Furthermore, the findings advance this visibility framework by suggesting that the predictability of visible condition-related events may impact upon CWE's and parents' decisions to communicate about epilepsy. To the author's knowledge, the present study is the first to support and develop elements of these theories for application to CWE's and parents' engagements in epilepsy-specific communication.

This study's largest contribution to research lies in its addition of empirical evidence to the limited body of research literature surrounding parent-child communication in families of CWE. Prior to the conduct of this research, a dearth of literature existed investigating parent-child communication about epilepsy. The presence of research surrounding parent-child communication about other chronic illnesses was noted, however, given epilepsy's unique invisible and unpredictable symptomatology, a specific exploratory inquiry was of importance. This is the first study to examine how CWE and parents talk about epilepsy and the impact that such communication has on their psychosocial wellbeing. Key findings of this thesis contributing unique knowledge to the field of childhood epilepsy include; the impact of condition invisibility and CWE and parents' engagements about epilepsy, the importance of epilepsy-related knowledge in facilitating parent-child epilepsy-related communication, the potential barriers that normalcy seeking and avoiding worry present for CWE and parents when choosing to discuss epilepsy together, the sensitive nature of epilepsy-related conversations surrounding issues of CWE autonomy, and the strong association observed between epilepsy-related attitudes and epilepsy-related communication approaches. The empirical evidence revealed within this study has demonstrated the impact that parent-child epilepsy-related communication may have on the wellbeing of CWE and their parents, advocating for the development of a family-based communication intervention to order to promote positive psychosocial outcomes.

In terms of the methodology employed, this study contributes to knowledge surrounding mixed methodologies and their use in family healthcare research. The present study supports research seeking to include the voice of the child when examining child perspectives on an issue. Furthermore, this study promotes the gathering of dual perspectives within communication research. By gathering both CWE and parent perspectives, key information has been identified regarding the differing barriers, enablers, and consequences of parent-child dialogue about

epilepsy for both parties. A distinct methodological contribution of the present study lies in the design of a new measure examining parent-child communication about epilepsy for use with CWE and parents of CWE. This newly developed measure may contribute to future research in the area of parent-child communication about epilepsy by providing an assessment of how CWE and parents engage in epilepsy-specific dialogue. Finally, key information has been elucidated regarding the conduct of a sequential exploratory mixed method design in examining the aims of the present study. This study has benefited from a mixed-method approach by allowing for the qualitative phase to pinpoint specific areas of parent-child epilepsy-related communication for examination in the quantitative phase. It is anticipated that this information, and an explicit appraisal of the strengths and limitations of this study, will aid in the conduct of future research in the area of parent-child communication about chronic illness.

Considering the contextual and practical contributions of this research, the present study is the first to examine the communication experiences of families living with epilepsy in Ireland. Furthermore, this research is the first to investigate how CWE and parents communicate about epilepsy specifically. This research is of particular importance in light of the current state of healthcare services for people living with epilepsy nationally. Epilepsy is at the foreground of National and International health agendas. Regionally, Irish health care is at an important juncture with the establishment of twenty Clinical Care Programmes under the Quality and Clinical Care Directorate. Epilepsy is one area targeted by the Irish Health Service Executive with the formation of a National Epilepsy Programme. This research will be instrumental in contributing to this agenda as consulting directly with CWE and their parents will enable enhanced understanding of their perspectives which will assist policy-makers and health professionals devise and implement better healthcare communication practices for CWE and their families.

11.2 Strengths and Limitations of the Mixed-Methods Study

To the author's knowledge, this is the first mixed-method study to examine CWE's and parents' perspectives of engaging in dialogue about epilepsy with one another, in addition to explicating the relationship between the epilepsy-related communicative patterns of CWE/parents of CWE and their psychosocial wellbeing. A major strength of the present study is the inclusion of the child's voice as, historically, often solely parent-proxy perspectives have been accessed within illness-related communication research (Sherifali & Pinelli, 2007). This research highlights the need to include CWE and their parents in the construction of healthcare policy in Ireland, specifically concerning the needs of families living with

childhood epilepsy. By including the perspectives of both CWE and their parents, a richer insight is provided relating to the differing communicative needs of both parties. Another important strength of the present study is reflected in the mixed method approach used. Specifically, integration of the qualitative and quantitative findings has allowed for rich insights into how CWE and their parents communicate about epilepsy.

Despite the strengths of this exploratory mixed-methods study, some methodological limitations are noted. For the purpose of this mixed-method study, the experiences of CWE and parents of CWE with no significant comorbidities were accessed. CWE living with significant comorbidities and their parents may face additional challenges when communicating about other impactful conditions. By accessing the experiences of CWE with no comorbidities and their parents, the findings of this study provide insight into parent-child dialogue purely related to epilepsy. Therefore, the present samples cannot be considered representative of all CWE and their parents. However, preliminary evidence for the applicability of these findings to other contextual settings has been demonstrated via engagements at national and international meetings where the mixed-methods objectives and findings of this study have held resonance with health care professionals who communicate with families of CWE. Another possible limitation of this study lies in the lack of directionality within the results' inferences. Through using correlational analyses to investigate the relationship between parent-child dialogue about epilepsy and psychosocial wellbeing, novel associations have been established between; 1) open communication about epilepsy and positive psychosocial wellbeing for CWE and parents, and 2) closed communication about epilepsy and poorer psychosocial wellbeing for CWE and parents. However, the bidirectional influences of these variables must also be considered. For example, whilst it is possible that open parent-child dialogue about epilepsy leads to more positive psychosocial wellbeing, it is also possible that positive psychosocial wellbeing leads to more open dialoguing about the condition. Future research is required to ascertain the directionality of the associations demonstrated in the present study.

11.3 Study Implications

The present research is pioneering in its investigation of parent-child communication about epilepsy and reveals valuable novel findings relating to CWE's and parents' experiences of talking about epilepsy within the home. The findings of this study have important future implications for practice, policy, and research stakeholders.

11.3.1 Practice Implications

The practice implications of the present study have particular relevance to HCPs working with families living with childhood epilepsy, and epilepsy support organisations. HCPs working closely with families of CWE play a pivotal role in creating an environment where CWE and parents feel comfortable communicating about epilepsy. The following recommendations might facilitate this aim:

- HCPs should be cognisant of the challenges CWE and parents experience in understanding and retaining information at the time point of diagnosis.
- With many different epilepsy types, each with different symptoms/seizures and associated treatments, it is imperative that HCPs tailor their communication to each parent's need for specific information about their child's epilepsy diagnosis classification. Enhanced parental understanding of their child's epilepsy condition could instill greater confidence in parents when conversing with CWE about his/her condition.
- HCPs should endeavour to provide child-friendly, epilepsy-related information for CWE to facilitate greater ease of communication between parents and CWE in relation to their condition. This information would also enable parents to translate epilepsy-related information into developmentally appropriate language for their child.
- HCPs should be cognisant of the impact the struggle for normalcy can have on parent-child communication about epilepsy. CWE's avoidance of communication about their epilepsy in an attempt to avert parental worry and dispel any parental fuss could have implications for the health and safety of the child, especially if this avoidance is associated with CWE adopting suboptimal self-management behaviours.

Epilepsy support organisations also play a role in alleviating challenges that CWE and parents face when communicating about epilepsy together. The following recommendations may aid such organisations in providing an utmost level of support for these families:

- The provision of age-appropriate tailored epilepsy-related information for CWE and parents in relation to their specific epilepsy and seizure type may enable CWE and parents to feel greater-informed about epilepsy. The findings of the present

study have demonstrated the beneficial impact that epilepsy-related knowledge has on parent-child dialogue about the condition.

- The findings unearthed here provide evidence for the challenges that the invisibility of epilepsy present for CWE and parents when faced with talking about the condition. CWE and their parents face specific challenges due to the stigma that surround epilepsy within society. A national public awareness campaign, initiated by a support organization, aimed at demystifying the invisible nature of epilepsy could aid in reducing epilepsy-related stigma which this study has demonstrated may promote less perceived stigma for CWE and parents and subsequently more open communication relating to epilepsy within the home.

11.3.2 Policy Implications

The findings of this mixed-method study raise a number of policy implications that may be tackled in an effort to facilitate a greater level of parent-child communication about epilepsy.

- Findings unearthed within the present study will provide valuable information for use within the National Epilepsy Care Programme in Ireland, aiming to deliver the best standard of care for individuals living with epilepsy. This Programme will benefit from findings uncovered in this study relating to CWE's and parents' diagnosis experiences and with the role HCPs play in communicating an epilepsy diagnosis to families.
- The future of research within the field of epilepsy in Ireland would benefit from the creation of a national database of children living with epilepsy. The present study has highlighted issues relating to recruitment with regard to accessing large pools of potential participants (i.e. – CWE and their parents). The establishment of a national clinical database would aid researchers in expanding their recruitment base and therefore providing larger scale empirical evidence surrounding CWE's and parents' psychosocial care needs.

11.3.3 Research Implications

Though the present study is exploratory in nature and covers a number of areas relating to parent-child communication about epilepsy, future research is necessary to address particular questions that have arisen over the course of this study.

- How parents are guided at the time point of diagnosis in relation to imparting epilepsy-related knowledge to CWE remains an under researched area and warrants

investigation in the future. Future research should seek to examine the efficacy of educational interventions at the time point of diagnosis for CWE and parents with regard to their subsequent adjustment and psychosocial wellbeing.

- CWE and parents face differing challenges when talking about epilepsy depending on how long CWE have lived with their condition. Longitudinal research is required to examine parent-child dialogue over time as families navigate the trajectory of their CWE's condition.
- Further research is necessary to ascertain the impact of epilepsy-related stigma on the adoption of closed parent-child communication strategies surrounding epilepsy, and their subsequent impact on CWE and parents' psychosocial wellbeing.
- Sensitive conversations relating to the causes and trajectory of epilepsy were unearthed as a communicative challenge in the present study. Future studies should endeavour to examine parent-child communication relating to epilepsy causes and trajectories, as opposed to solely the symptomatology, in order to aid parents in navigating these conversations.
- The concept of parent knowledge about epilepsy, and their affordance of greater autonomy to CWE, acting as an enabler of parent-child communication about epilepsy and the role this could play in an effective family-based communication intervention for CWE and parents warrants greater attention in future research.
- Future research investigating the potential impact of gender and clinical factors on epilepsy-related communication within the home and the challenges that CWE and parents face is recommended. Studies in the area of family communication about epilepsy should seek to replicate the present study with a more varied parent population (including a greater number of fathers) and a wider range of seizure characteristics amongst CWE.
- Findings of the present study solely reflect CWE's and parents' experiences of communicating about epilepsy together. Future research should seek to investigate epilepsy-related communication with other family members (e.g. – siblings) in order to examine how epilepsy is talked about more broadly within the family unit.
- The present study focused solely on the communicative experiences of CWE with no comorbid conditions and their parents. Future research should endeavor to expand upon these findings by investigating parent-child communication about epilepsy amongst CWE with comorbid conditions in order to ascertain any differences in the way they and their parents engage in dialogue about epilepsy.

- The newly developed Parent-Child Communication about Epilepsy Questionnaire measure represents a key contribution to epilepsy-related communication research. Future research further assessing this measure's psychometric properties with CWE and their parents is recommended.

11.4 Conclusion

This research presents the first investigation of parent-child communication about epilepsy and epilepsy-related issues. The present study provides a unique contribution to the literature by enabling a greater understanding of the communication that occurs between CWE and their parents and the impact this has on their daily lives. The findings suggest that, for both CWE and parents, open communication relating to epilepsy leads to positive psychosocial outcomes and promotes greater wellbeing. Conversely, not talking about epilepsy, or talking about epilepsy-related restrictions, may result in poorer outcomes for both CWE and their parents. Key enablers of epilepsy-related communication include a greater level of epilepsy-related knowledge and affording CWE greater autonomy in relation to epilepsy. It is important for these areas to be targeted within family-based communication interventions for families of CWE, seeking to enhance effective parent-child communication about epilepsy. These findings have important implications for individuals working with families of CWE, such as HCPs. By helping to facilitate open communication about epilepsy, the greatest level of psychosocial wellbeing may be ensured for CWE and their parents.

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Appendix A: Systematic Review Findings

Author (year), Country	Aims	Study Design	Method/Measures	Sample	Recruitment source	Findings related to family communication about epilepsy
Austin et al. (2002) United States	To assess the feasibility of a psychoeducational family intervention, entitled "Be Seizure Smart", aimed at improving attitudes and increasing family functioning.	Mixed-method feasibility study of psychoeducational intervention	**Method:** • Pre-intervention assessment • "Be Seizure Smart" intervention process • Post-intervention assessment (Pre and post-intervention assessments were conducted via structured phone interviews in which psychometric instruments were used) **Measures:** Child participants: *General concerns/fears* • 13-item scale developed by the authors based on the most common concerns and worries identified in past research *General knowledge about seizures* • 14-item scale developed by the authors to reflect common myths about epilepsy and its effects. *Psychosocial care needs (information and support)* • Child Report of Psychosocial Care Scale *Attitude* • Child Attitude Toward Illness Scale (CATIS) *Family functioning* • Revised Family APGAR Parent participants: *General concerns/fears* • 9-item scale developed by the authors based on the most common concerns and worries identified in past research *Concerns about seizure management* • 8-item scale developed by the authors to measure parents' concerns or worries related to managing their child's epilepsy *General knowledge about seizures* • 20-item scale developed by the authors to reflect common myths about epilepsy and its effects. *Psychosocial care needs (information and support)* • Parent Report of Psychosocial Care Scale *Attitude* • Parent Mood Scale *Family functioning* • Family APGAR	N = 10, families of children with epilepsy Subgroup A: n = 9*, children with epilepsy (aged 7 – 13 years) *One child was unable to complete the interview due to a learning disability) Subgroup B: n = 15, family members of children with epilepsy (Mothers, n = 8; Grandmothers, n = 1; Fathers, n = 2; Siblings, n = 4)	Paediatric Neurology Clinic	• Children had significantly higher family functioning scores* after the intervention than before. • Parents' post-intervention scores also indicated a higher level of family functioning*, though this result was not found to be statistically significant. *As measured by the Family APGAR/Revised Family APGAR measures, in which family communication is a measured component.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Chavez & Buriel (1988) United States	To examine the mother-child interactions of immigrant and native-born Mexican American mothers with a child with epilepsy	Quantitative cross sectional design	**Method:** • Structured beanbag toss game videotaped and analysed according to maternal, child and dyadic behaviours.	N = 79, parent/child (aged 4 – 10 years) dyads Subgroup A: n = 29, parent/child with epilepsy dyads Subgroup B: n = 26, parent/child with asthma dyads Subgroup C: n = 24, parent/child dyads (Healthy control group)	Paediatric Hospital	• In contrast to mothers with a child with asthma or in good health, mothers with a child with epilepsy used fewer verbal directions and exhibited fewer positive responses following successful task completion by the child. • Mothers with a child with epilepsy also used more nonverbal directions, commands, and physical guidance when compared to mothers with a child with asthma or in good health.
Coulter &Koester (1985) United States	To identify the information needs of parents of children with epilepsy with a view to developing appropriate interventions to improve physician's communication with these parents.	Quantitative cross sectional design	**Method:** • Interviews (Q-sort task administered in which concerns about the child with epilepsy were ranked)	N = 29, primary caregivers of children with epilepsy and physicians. Subgroup A: n = 24, primary caregivers of children with epilepsy (aged 6 – 16 years) (Mothers, n = 19; Fathers, n = 4; Grandmothers, n = 1) Subgroup B: n = 5, physicians with direct experience in caring for children with epilepsy	Paediatric Epilepsy Clinic	• Parent concerns related to their relationship with their child included; - How to encourage their child to talk to them - How their child feels about them - How to handle their child's moods - Arguments with their child - Being strict enough with their child • Physicians underestimated the level of parental concern in relation to the parent-child relationship
Ferrari, Matthews & Barabas (1983) United States	To determine the adjustment of the family of a child with seizures relative to families of children with diabetes and to families in which no chronically ill children are present.	Quantitative cross sectional design	**Method:** • Semi-structured interviews (Four instruments administered) **Measures:** Child participants: • Draw-a-Person test • Multi-Dimensional Measure of Children's Perceptions of Control • Piers-Harris Children's Self-Concept Scale Parent participants: • Rochester Adaptive Behaviour Inventory (RABI)	N = 45, children (aged 6 – 12 years) and their families Subgroup A: children with diagnosed neuro-epileptic disorders (n = 15) Subgroup B: children with diagnosed diabetes (n = 15) Subgroup C: children with no known chronic illness or daily medication requirement (n = 15)	Unknown	• Families of children with epilepsy reported being significantly less close than families of children with diabetes and children with no illness. • Families of children with epilepsy reported that their discussions mostly concerned specific issues and problems compared to the more general topics of other families. • Children with epilepsy perceived themselves to be more problematic to their families than children with diabetes or non-chronically ill children.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Hanai (1996) Japan	To examine quality of life in school children with epilepsy	Quantitative cross sectional design	**Method:** • Questionnaires **Measures:** • Unknown (Not reported)	N = 344, Parents/family members of children living with epilepsy Subgroup A: n = 252, parents/family members of children attending ordinary classes. Subgroup B: n= 92, parents/family members of children receiving education in special classes or schools N = 1808, school teachers	Paediatric Neurology Outpatient Clinic	• In subgroup A, families explained the epilepsy to the child to the following extent; - "Explain in detail" (26%) - "Explain a little (23%) - "Explain only that seizures occurred" (31%) • In subgroup B, families explained the epilepsy to the child to the following extent; - "Explain in detail" (11%) - "Explain a little (17%) - "Other" (63%) – rationale: "children cannot understand even if families explain"
Herzer et al. (2010) United States	To describe and compare generic family functioning in children with five different chronic conditions and healthy comparisons, and to examine the relations between family functioning and socio-demographic variables.	Quantitative secondary data analysis across six studies	**Method:** • Questionnaire (A secondary data analysis from six independent studies) **Measures:** • Family Assessment Device (FAD) • Demographic and Medical History Questionnaire	N = 301, parents of children (aged 5 – 18 years) Subgroup A: n = 59, parents of children with cystic fibrosis Subgroup B: n = 28, parents of children with obesity Subgroup C: n = 44, parents of children with SCD Subgroup D: n = 43, parents of children with inflammatory bowel disease Subgroup E: n = 70, parents of children with epilepsy Subgroup F: n = 57, healthy comparison group	Subgroup A, B, D, E: Approached in clinic Subgroup C: Mail/Phone-call Subgroup F: Mail/ Approached in clinic	• 23% of families living with epilepsy endorsed "unhealthy levels of functioning" in terms of communication
Hightower et al. (2002) United States	To gain a better understanding of children's personal experiences with epilepsy to guide health care providers in providing care to these children	Qualitative exploratory design	**Method:** • Interviews (Guided by eight open-ended questions)	N = 8, children with epilepsy (aged 9 to 12 years)	Paediatric neurology clinic	• Parent-reported unwillingness of child to answer epilepsy-related questions

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Hirfanoglu et al. (2009) Turkey	To evaluate knowledge of, perceptions of, and attitudes towards epilepsy within the families of children with epilepsy.	Quantitative cross sectional design	**Method:** • Questionnaires **Measures:** Child participants: • Demographic information questionnaire • 12-item measure developed by the authors to measure knowledge about epilepsy. • 24-item measure developed by the authors to measure the impact of epilepsy on the child Parent participants: • Demographic information questionnaire • 13-item measure developed by the authors to measure knowledge about epilepsy • 16-item measure developed by the authors to measure the medical aspects of the child's epilepsy. • 14-item measure developed by the authors to measure the day-to-day influence of epilepsy on the child and the entire family	N = 533, children with epilepsy and their parents. Subgroup A: n = 220, children with epilepsy (aged 8 – 17 years) Subgroup B: n = 313, parents of children with epilepsy	Paediatric Neurology Department	• 20.9% of children reported not having enough support from their own families. • 63.2% of children reported that they were bothered by their parents following them around. • Almost 20% of parents did not sufficiently inform their children about epilepsy. • The more siblings a child with epilepsy had, the less knowledge about epilepsy he or she was likely to have. • Parents with a greater knowledge of epilepsy reported less restriction of family activities.
Hoare (1984) United Kingdom	To investigate the development of inappropriate dependency among children with epilepsy by comparing two groups, one with newly diagnosed epilepsy and one with chronic epilepsy.	Quantitative cross sectional design	**Method:** • Questionnaires **Measures:** • Self-Administered Dependency Questionnaire (SADQ)	N = 123, parents of children with epilepsy and diabetes Subgroup A: n = 29, parents of children with newly diagnosed epilepsy Subgroup B: n = 29, parents of children with newly diagnosed diabetes Subgroup C: n = 29, parents of children with chronic epilepsy Subgroup C: n = 36, parents of children with chronic diabetes	Identification of participants through hospital case-notes and personal contact with nine consultant paediatricians	• Children in the newly diagnosed and chronic epilepsy groups were significantly more dependent on their parents than children in the general population. • In contrast to children with chronic epilepsy, those with chronic diabetes did not differ from children in the general population on 15 of the 16 measures of dependency. Therefore, inappropriate dependency is not an invariable accompaniment of chronic disease, but depends on the nature of the illness.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Hoare & Kerley (1991) United Kingdom	To investigate the impact of epilepsy on the psychological wellbeing and social adjustment of children with epilepsy and their families, and to identify factors associated with poor adaptation to epilepsy and its treatment.	Quantitative cross sectional design	**Method:** • Semi-structured interviews **Measures:** • Edinburgh Parental Attitude Scale to Epilepsy (EPASE) • Rutter Parent and Teacher Questionnaires • Piers-Harris Questionnaire • Self-Administered Dependency(SADQ) • General Health Questionnaire (30) • Golombok-Rush Inventory of Marital Satisfaction (GRIMS) • Holroyd Questionnaire on Resources and Stress	N = 108, parents of children with epilepsy (Mean Age: 10.4 years)	Paediatric Epilepsy Clinic	• Analysis of the Self-Administered Dependency Questionnaire (SADQ) indicated that secondary school-aged boys with epilepsy differed significantly from children in the general population on the communication subscale, i.e. – frequency of communication with parents.
Hodes, Garralda, Rose & Schwartz (1999) United Kingdom	To examine family relationships of children with epilepsy and the association with high risk for psychiatric disorder using maternal expressed emotion (EE).	Quantitative cross sectional design	**Method:** • Semi-structured interviews (Questionnaires/Instruments administered) **Measures:** Child participants: • Birleson Depression Self-Rating Scale (DSRS) 'What Am I Like' Self-Perception Profile for Children Parent participants: • Camberwell Family Interview • Parental and Teacher Rutter Behavioural Scales • General Health Questionnaire (GHQ) • Social Stress and Supports Interview	N = 22, families of a child with epilepsy attending ordinary school. Subgroup A: n = 22, schoolchildren with epilepsy (aged 8 – 17 years) Subgroup B: n = 22, mothers of schoolchildren with epilepsy Subgroup C: n = 16, healthy siblings of children with epilepsy	Paediatric outpatient clinic	• There was significantly higher emotional over-involvement towards children with epilepsy than towards healthy controls. • There was a near significant trend for mothers to express more hostile comments towards their children with epilepsy.
Hodgman et al. (1979) United States	To examine the interrelations of neurologic examination, seizure control, and selected behavioral items in adolescents with grand mal epilepsy.	Mixed-method research design	**Method:** • Interview • Questionnaire • Neurological Evaluation	N = 25, adolescents with grand mal epilepsy (aged 14 – 18 years) and their parents	Paediatric neurology clinic	• The better the seizure control, the less likely adolescents had asked what happens to people with epilepsy (r = - 0.45); or wished to speak more openly with parents or siblings about epilepsy (r = - 0.55). • The better the seizure control, the less the adolescent had discussed his/her epilepsy • Parents of adolescents with poor seizure control tended to deny the condition (r = -0.55); their children also accurately felt themselves to be in poorer health (r = -.044)

Author (year) Country	Aims	Study Design	Method/Measures	Sample	Recruitment source	Findings related to family communication about epilepsy
Jantzen et al. (2009) Germany	To present the development, contents, and efficacy of the FLIP&FLAP programme for children and adolescents with epilepsy, and their parents.	Mixed-method feasibility study of a family-focused intervention	**Method:** • Interviews • Focus groups • Video feedback • Questionnaires (as part of a multi-centre non-randomised two-group pre/post trial) **Measures:** Parent participants: • Descriptive/Demographic information • Epilepsy Knowledge Profile (EKP-G) • 4-item scale developed by the authors to measure parent-reported child self-management skills. • 13-item scale developed by the authors to measure child's independence in everyday activities • 13-item questionnaire developed by the authors to assess the effect of the FLIP&FLAP intervention on disease-related worries of carers. • 1-item on child ability to disclose epilepsy to others • ZUF-8 questionnaire Child participants: • 27-item questionnaire developed by the authors to measure epilepsy knowledge • DISABKIDS Modular HRQOL questionnaire • 1-item on ability to disclose epilepsy to others	N = 279, children with epilepsy and their parents Subgroup A: Intervention Group (IG) - n = 21, children with epilepsy (aged 8 – 11 years) - n = 44, adolescents with epilepsy (aged 12 – 16 years) - n = 72, parents of children with epilepsy Subgroup B: Waiting Control Group (WCG) - n = 31, children with epilepsy - n = 39, adolescents with epilepsy - n = 72, parents of children with epilepsy	10 German Epilepsy Centres	• Parents (N = 67) of the Intervention Group reported decreased direct carer control and increased self-management of their child when compared to the Working Control Group (N = 67) (significant time-by-group effect), with medium to large effect size (d = 0.7) • Children's and adolescents' self-reported ability to explain epilepsy increased (significant time-effect), but there was no difference between the Intervention Group (N = 58) and the Working Control Group (N = 59). • Quite a few parents displayed seemingly irrational anxieties concerning their child's epilepsy. As a consequence, some parents relieved their fears by becoming overprotective. • Many parents demonstrated uncertainty as to whether certain behaviours their child exhibited were epilepsy-related. Resulting anxious observation of the child led in some families to a permanent nervous tension and uncertainty on the part of the parents as to the appropriate educational approach to adopt. • Many parents found it difficult to relay epilepsy-related information to their child due to their own lack of medical understanding. • A considerable number of parents' were keen to protect their child from having to deal with his/her epilepsy. • Many parents underestimated their child's ability to take responsibility for their epilepsy. Some even suppressed the child's attempts to do this.
Kitamoto et al. (1988) Japan	To investigate the attitudes of parents toward their child with epilepsy and clarify factors influencing these child-parent relationships.	Quantitative cross sectional design	**Method:** • "Taken" diagnostic test for child-parent relationships **Measures:** • "Taken" diagnostic test in which undesirable attitudes of parents towards children were categorized into 10 constructs (each measured with 10 questions); - Negative rejection - Positive rejection - Strictness - Expectation - Interference - Anxiety - Blind obedience - Dotage - Inconsistency - Disagreement	N = 70, children with epilepsy (aged 6 – 15 years) and their parents. Subgroup A: n = 35, children with epilepsy (and no other neurologic complications) and their parents (27 mothers, 11 fathers) Subgroup B: n = 35, children with epilepsy (and mental or motor disabilities) and their parents (32 mothers, 5 fathers)	Unknown	• Mothers of children in group A showed a positive rejection towards their child in cases where the duration of their epilepsy was less than 5 years. • Mothers of children in group A were also reported to show a positive rejection towards their child in cases where seizures were controlled and not persistent. • Mothers of children in group B showed abnormal attitudes in terms of anxiety and dotage to ward their children over the age of 12 years, compared to those under 12. This finding was not replicated in group A. • Mothers of children in group B also frequently showed anxiety and dotage, but neither strictness nor interference, when seizures were not controlled. This finding was not replicated in group A.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Lothman & Pianta (1993) United States	To investigate the role of child-mother interactions in the psychosocial adjustment of children with epilepsy.	Quantitative cross-sectional design	**Method:** • Questionnaires • Observed Child Problem-Solving Tasks • Observed Parent-Child Problem-solving Tasks **Measures:** Parent/child participants: Three 7-point global scales were used to rate each of the observed mother-child interaction tasks; • Mother's support for task completion • Child's self-reliance • Availability of affect (dyadic scale) Parent participants: • Family Life Events scale • Medical Risk Index Child participants: • Confidence scale • Task Involvement scale Teacher participants: • Teacher Rating Scale	N = 59, mother/child with epilepsy (aged 7 – 13 years) dyads (Mean Age: 9.5 years) N = unspecified, teachers of included children with epilepsy	Paediatric Neurology Clinics Private Paediatric Practices Private Neurology Practices	• Mother-child interaction ratings were highly related to the child's problem-solving behaviour without the mother present. • A strong relation was found between the ratings of mothers' support/availability and child's competence/involvement in the independent problem-solving task. • Quality of the parent-child relationship (as measured by the child's self-reliance) influenced the child's competence in independent problem solving.
McEwan et al. (2004) United Kingdom	To describe quality of life in adolescents with epilepsy from the direct perspective of adolescents and consider issues in the context of a developmental perspective	Qualitative exploratory design	**Method:** • Focus groups	N = 22, adolescents with epilepsy (aged 12 – 18 years)	Paediatric neurology clinic	• Significant theme of "the development of autonomy" emerged • Adolescents largely reported parents as being over-protective • 6 adolescents reported parental over-protection as reduced with an increase in parent's knowledge about epilepsy
McNelis et al. (2007) United States	To explore in-depth the self-reported concerns and needs of children with epilepsy and their parents	Qualitative exploratory design	**Method:** • Focus groups (2 child focus groups, 2 parent focus groups)	N = 26, children with epilepsy and parents of children with epilepsy. Subgroup A: n = 11, children with epilepsy Subgroup B: n = 15, parents of children with epilepsy	Epilepsy support groups	• Parents noted lack of information as a struggle for communicating with their children as they aimed to provide easy-to-understand descriptions of epilepsy. • Parents identified themselves as role models for how children perceived their epilepsy • Parents reported family role changes in response to epilepsy

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Moffat et al. (2009) United Kingdom	To investigate the impact of childhood epilepsy on quality of life directly from the child's perspective	Qualitative exploratory design	**Method:** • Focus groups • Interviews	N = 22, children with epilepsy Subgroup A: children aged 7-8 years (n = 9) Subgroup B: children aged 9-10 years (n = 9) Subgroup C: children aged 11-12 years (n = 4)	Paediatric neuroscience centre	• Emergent themes for 7 – 8 year olds: - Family wanting epilepsy to be a secret - Parents worrying too much about epilepsy - Sleeping with parents because of epilepsy - Parents imposing restrictions • Emergent themes for 9 – 10 year olds; - Parents keeping you safe - Parents helping you during seizures • Emergent themes for 11 – 12 year olds; - Parents treating siblings differently (less restrictions on siblings)
Mu (2008) Taiwan	To investigate the essence of the family health-illness transition experience from the parental perspective when a child is afflicted with epilepsy.	Qualitative phenomenological design	**Method:** • Semi-structured interviews	N = 10*, parent couples of children with epilepsy (aged 3 – 6 years) *In two cases, fathers could not participate due to work commitments	Purposive sampling via two medical centres in Taiwan	• The word "epilepsy" was seldom used or openly discussed within the family during the first one and a half years following the diagnosis of epilepsy. This was due to parents' suffering from the negative social connotation of epilepsy and parental perceptions of epilepsy as an unacceptable illness. • Parents of children with epilepsy strove to strengthen their parenting patterns by enhancing parental abilities, monitoring and mastering the treatment and establishing a mutually respectful and accepting family environment. • Parents endeavoured to establish appropriate family interaction patterns for their child's development by modifying their caregiving behaviour and expectations for the child. They did this by encouraging and supporting their child's appropriate behaviour. • Parents established reasonable parenting and disciplining styles for their child with epilepsy and ensured appropriate interaction patterns between siblings
Mu & Chang (2010) Taiwan	To examine the effect of a programme designed to reduce family boundary ambiguity in families who care for children with epilepsy.	Mixed-method research design	**Method:** • Semi-structured interviews • Check-list of parental needs • Parental education information handbook • Questionnaire **Measures:** • Checklist of parental needs (ranking instrument developed by the authors for the purpose of this study) • Boundary Ambiguity Scale for Children with Chronic Illness • Beck Depression Inventory	N = 78, mothers of children with epilepsy	Two major medical centres in Taiwan	• "Maintaining family stability and harmony" was ranked by parents as one of the top two parental needs within the parent coping strategies domain. • The top-ranked needs of the interaction between family and society domain were "appropriate interactions with the child" and "family adaptability".

Author (year), Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Mulder & Suurmeijer (1977) Netherlands	To describe interactions between the family and the child with epilepsy, specifically examining parents' efforts to obtain help for their child and the effect of their child's epilepsy on family relationships.	Qualitative exploratory design	**Method:** • Interviews (Separate interviews conducted with children and parents)	N = 13, children with epilepsy (aged 10 – 16 years) and their parents* *Unclear whether one or both parents participated. **Two of these children were siblings from the same family	Regional Outpatient Department of a Special Centre for Epilepsy (n = 10 families) Regional Outpatient Department of a University Hospital (n = 2 families)	• At the onset of the epilepsy, parents felt that they should spend more time and care on their child with epilepsy despite this being at the cost of other children. • With one exception, all mothers reported that their child with epilepsy needs more attention than their other children. • Generally, mothers were reported as more affectionate and controlling than fathers of children with epilepsy. • In one case, a parent told their child not to use the word "epilepsy". • In four families the attitude of the father was considered to be more or less rejecting (in two families the children confirmed this).
Nicholas & Pianta (1994) United States	To examine the relations among seizure control, child-parent interactions, and child behaviour problems in children with epilepsy and their mothers.	Mixed-method research design	**Method:** • Interview • Questionnaire • Observation **Measures:** • Demographic Questionnaire • Mother-Child problem-solving tasks (2) • Child problem-solving task (1) • Child Behaviour Profile (for completion by child's teacher) • Child Behaviour Checklist (for completion by child's mother)	N = 59, children with epilepsy (aged 7 – 13 years), their mothers and their teachers	Paediatric Neurology Clinics Private Paediatric Practices Private Neurology Practices	• Patterns of parent-child interaction and children's confidence in problem-solving are predictive of social problems in children with epilepsy independent of seizure control.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Ritchie (1981) Australia	To investigate an alternative model of family behaviour in which the behaviour of the family with an epileptic child is conceptualized as the adaptive reaction of an interdependent group to a crisis situation.	Quantitative cross-sectional design	**Method:** • Questionnaires • Observed task **Measures:** • Two-part questionnaire developed for the study including some previously used items by O' Connor (1967) and others designed by the investigator • Family problem-solving task	N = 30, families consisting of a tetrad of mother, father, elder and younger sibling Subgroup A: n = 15, families of a child with epilepsy Subgroup B: n = 15, control families	Hospital neurology department Local schools	• In families of a child with epilepsy, the mother was found to take a more prominent role in family discussions when compared to control families. • In families of a child with epilepsy, the mother was found to be the dominant speaker (in 12 of 15 cases) compared to the father ($p< 0.05$) • Children with epilepsy were reported to take a position of reduced involvement compared to the older sibling in control families. • *Adaptation;* - A significant difference in the mean number of changes of opinion in the direction of consensus between families living with epilepsy and control families was seen ($p = <0.025$). - i.e. – Families of a child with epilepsy were more likely to conform to group opinion. • *Cohesion;* - A significant difference in the mean number of unsuccessful interruptions between families living with epilepsy and control families was seen ($p = 0.025$) - i.e. – Families of a child with epilepsy tended to acknowledge interruptions more frequently than control families • *Decision-making style;* - Families of a child with epilepsy reached decisions more frequently than control families
Ronen et al. (1999) Canada	To identify the attributes of health-related quality of life in childhood epilepsy according to children with epilepsy and their parents.	Qualitative exploratory design	**Method:** • Focus groups (9 child focus groups, 17 parent focus groups)	N = 29, children with epilepsy and their parents Subgroup A: n = 29, children with epilepsy (aged 6 – 10 years) Subgroup B: n = 42, Parents of children with epilepsy (28 M and 14 F)	Child/ Adolescent Epilepsy Programme Database (within the regional centre of a Paediatric Hospital)	• Parents felt that they should not use the word "epilepsy" when communicating with their child in order to discourage him/her using this term in social situations; this was largely due to parental fear of their child being stigmatized by others. • Parental fear in response to the child's seizures was expressed during parent-child interactions.

Author (year) Country	**Aims**	**Study Design**	**Method/Measures**	**Sample**	**Recruitment source**	**Findings related to family communication about epilepsy**
Stores & Piran (1978) United Kingdom	To explore the possibility that dependency might occur differently in boys and girls with epilepsy	Quantitative cross-sectional design	**Method:** • Questionnaires • EEG investigations **Measures:** • Self-Administered Dependency Questionnaire (SADQ)	N = 65, mothers of children with epilepsy attending ordinary school	Paediatric hospital neurology department	• Compared to boys with no known illness, boys with epilepsy scored significantly higher on the affection subscale of the SADQ. • Compared to boys with no known illness, boys with epilepsy scored significantly lower on the communication subscale of the SADQ.
Tzoufi et al. (2005) Greece	To investigate the family characteristics of Greek children suffering from childhood chronic neurological diseases (CND)	Quantitative cross-sectional design	**Method:** • Questionnaires **Measures:** • Family Environmental Scale (FES) • Family Burden Scale • General Health Questionnaire (GHQ) • Questionnaire developed by the authors to measure parental knowledge of their child's illness	N = 82, parents of children with chronic neurological diseases (CND) or other common paediatric illnesses • Subgroup A: n = 52, parents of children with CND *Subgroup A[1] = n = 37, parents of children with epilepsy* *Subgroup A[2] = n = 15, parents of children with other CND* • Subgroup B: n = 30, parents of children hospitalized with common paediatric illnesses	Paediatric neurology outpatient clinic (Every fifth child who was admitted for common paediatric problems)	• Families of children with CND scored significantly lower scores on the Expressiveness subscale of the Family Environmental Scale (measuring how open family members discuss issues, how freely they discuss their personal problems, etc., $p < 0.03$). • Families of children with CND scored significantly higher scores on the Conflict subscale of the Family Environmental Scale ($p<0.03$) • Families of children with epilepsy scored significantly higher scores on the Active-Recreational subscale of the Family Environmental Scale than families of children with other CND ($p < 0.01$).

Appendix B: Ethical Approval (Phase One)

Appendix B1: DCU Ethical Approval (Phase One)

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr. Veronica Lambert,
School of Nursing and Human Sciences

17th July 2013

REC Reference: DCUREC/2013/142

Proposal Title: A Qualitative Exploration of Family Communication about Epilepsy and its Associated Stigma Phase One of a Study Entitled: Demystify the Veil of Secrecy: A Mixed Method Inquiry of Parent-Child Dialogue about Epilepsy and its Associated Stigma.

Applicants: Dr. Veronica Lambert, Ms. Stephanie O'Toole et al.

Dear Veronica,

Further to review, the DCU Research Ethics Committee approves this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

DCU Research & Innovation

Dónal O'Mathúna

Dr. Donal O'Mathuna
Chairperson
DCU Research Ethics Committee

Taighde & Nuálaíocht Tacaíocht
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Appendix B2: TSCUH Ethical Approval (Phase One)

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Dr. Amre Shahwan
Consultant Clinical Neurophysiologist and Epileptologist
Neurology Department
Temple Street Children's University Hospital
Temple Street
Dublin 1

29th May 2013

Re: 13.017. A qualitative exploratory study of the impact that parents' perceptions of epilepsy might have on children's perceptions of their epilepsy.

Dear Dr. Shahwan,

The Ethics Committee has received and reviewed the revised research proposal form that successfully addressed the recommendations previously made by the Committee.

The Committee is now in a position to grant ethical approval for your project.

Yours sincerely,

pp/ Aránzazu Bartolomé

Prof Philip D Mayne
Medical Secretary Ethics Committee
MCRN: 08935

c.c. Department of Research

Appendix C: Recruitment Materials (Phase One)

Appendix C1: Parent Consent Form (Phase One)

Research Study: Families talking about epilepsy

PARENT CONSENT FORM

We are doing this study to try and find out more about you and your child's experiences of living with epilepsy. In particular, we are interested in you and your child's experiences of talking to each other and others about his/her condition and how these experiences were for you and your child.

This Epilepsy Ireland and Health Research Board (HRB) funded study is being carried out by Stephanie O' Toole (the researcher), Dr. Veronica Lambert and Professor Pamela Gallagher from the School of Nursing and Human Sciences at Dublin City University (DCU). This research study was developed in conjunction with the Neurology Department of Temple Street Children's University Hospital and Epilepsy Ireland - The Irish Epilepsy Association.

Participants' name(s) (Please list here *your name(s)* and the full names of *all your children* aged 6-15 living with epilepsy that you consent to participate)**:**

Parent Name (1): _____

Parent Name (2): _____

Child Name: _____

Child Name: _____

Child Name: _____

Child Name: _____

- I confirm that I have read and understood the Information Leaflet for this research study and have received an explanation of the nature, purpose, duration of the study, what myself and my child/children's involvement will be and any possible risks to myself or my family.
- I have had time to consider whether I want myself and my child/children to take part in this research. I understand that participation in the study is voluntary, (that is, I have a choice as to whether I consent to my child/children and I taking part). I have the contact details of the researchers and they have answered any questions I might have.

- I understand also that I am free to end my participation at any time by contacting Stephanie and this will not affect my family's or my child's present or future association with any of the services connected with the research, including medical care.
- I confirm that I have explained the research to my child/children.
- I give consent for my child/children as named above to take part in this research.
- (If you choose this option, thank you, please complete the details overleaf)
- I give consent for my own participation in this research

(One or two parent(s) please sign below)

Your name	Date	Signature
Your name	Date	Signature
Researcher's name	Date	Signature

Demographic Information

Thank you for agreeing to take part! We would be delighted if you would fill in some details about yourself and your family below. This information will only be used to help the researcher contact you for this research only.

Details:

Parent(s) name(s): _____
_____

Address: _____
_____
_____

Telephone number**:** _____

Is it OK to leave a voice mail on this phone? Yes □ No □

When is usually the best time to call? Morning □
Afternoon □
Evening □

Email address: _____

How would you prefer we contact you? By telephone □
By email □
By post □
I don't mind □

Thank you very much for taking the time to read the information leaflets and fill this form out.
We look forward to meeting you soon!

Appendix C2: Child Assent Form (Phase One)

CHILD ASSENT FORM

Families talking about epilepsy

- I, _____, agree to take part in this project, to talk to Stephanie and to draw pictures about what it is like talking about my epilepsy.
- I understand that there are no right or wrong things to say or draw, Stephanie is just really interested in knowing my story.
- I know that what I tell Stephanie might help other children in the future.
- I know that I don't have to take part in this project, even if my Mum and Dad are ok with me taking part. No one will be annoyed if I decide to stop taking part at any time.
- I have been promised that anything I tell Stephanie will be kept as secret as possible.
- I know that I can ask Stephanie questions at any time, now or later.

I REALLY WANT TO TAKE PART IN THIS PROJECT;

Child Signature: _____

Researcher Signature: _____

Date: _____

Time: _____

Appendix C3: Young-Person Assent Form (Phase One)

YOUNG PERSON ASSENT FORM

Families talking about epilepsy

- I, _____, have agreed to take part in this project to help others to find out what it is like to have epilepsy and to talk about epilepsy at home.
- I understand that Stephanie is going to talk to me about my epilepsy and that there is no right or wrong things to say or draw. Stephanie is just really interested in knowing my story.
- I know this project might help other young people living with epilepsy in the future.
- I know that I don't have to take part in this project even if my parents are ok with me taking part. It is completely up to me whether I wish to decide to stop at any time. No one will be annoyed if I decide to stop taking part at any time.
- I have been promised that anything I tell Stephanie will be kept as confidential as possible.
- I know that I can ask Stephanie questions at any time, now or later.

I REALLY WANT TO TAKE PART IN THIS RESEARCH PROJECT;

Young Person Signature: _____

Researcher Signature: _____

Date: _____

Time: _____

Appendix C4: Parent Information Sheet (Phase One)

Research Study: Families talking about epilepsy

What is this study about?

We are doing this study to find out more about you and your child's experiences of living with epilepsy. We are particularly interested in hearing about you and your child's experiences of talking/not talking about epilepsy and the impact of your discussions on your opinions of epilepsy as a condition.

Who is conducting this study?

This study is being carried out by Stephanie O' Toole (the researcher), Dr. Veronica Lambert and Professor Pamela Gallagher from the School of Nursing and Human Sciences at Dublin City University (DCU). This study is Epilepsy Ireland/Health Research Board funded and was developed in collaboration with the Neurology Department of Temple Street Children's University Hospital and Epilepsy Ireland - The Irish Epilepsy Association.

I, Stephanie, am completing this work as part of my PhD studies and I am being supervised by Dr. Veronica Lambert and Professor Pamela Gallagher. I am currently a postgraduate research student at DCU and am the person you, and your child, will have most contact with if you, and your child, agree to take part.

If I give consent for my child/children and myself to take part what will we be asked to do?

- We would like to have an opportunity to speak with you as parents and any children in your family who are **between 6 and 15 years of age** and who have been diagnosed with epilepsy for more than 6 months. If you give consent for your child/children to take part, we will remind them that this does not mean they *have* to take part, just that if they want to take part, you have confirmed that it is OK for them to do so.

- Your child/children will also receive an information letter. It will be a simple, easier to read version. We would encourage you to discuss the information letter with your child/children.

How long will the process take?

- If you and your child/children would like to take part, we will arrange a time and place in the next few weeks that suit you to take part in the interview.
- The interview should take no longer than 45-60 minutes depending on how much your child/children and you as parents wish to speak to us about. You will have a chance to talk to me again before the interview itself.

What if we do not decide to take part?

- We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your child's treatment in Temple Street Children's University Hospital, nor will it prevent you from being a part of any support groups/ activities organised by Epilepsy Ireland in the future.

What type of questions will we be asked?

- I will sit down with you as parents and your child or children who are **6 years or older** to conduct interviews.

- Your child/children will be given the option of having their parents' with them at the time of interview or of being interviewed alone (if you do not wish to be present during the interview please let us know in advance). This will allow your child/children to personally voice their views on what it is like to have epilepsy and to talk about their condition.

- Additionally if both parents wish to participate you will also be given the option of being interviewed separately or together.

- You and your child/children will be asked questions e.g. when or where are you most likely to talk about the condition. This interview will be audio-recorded, with your and your child's permission.

What will be done with the information collected from us?

- Only the research team and possibly the examiners of my thesis will have access to your answers and these will be treated in the strictest of confidence at all times.

Any recordings of interviews will be transcribed and made anonymous (i.e. the written version of the interview will not have your or your child's name on it, but will be numbered so we can identify it later). All information from the study (i.e. recordings,

- consent forms, name keys etc.) will be destroyed after my thesis has been examined. However, the transcribed interviews (which will now be completely anonymous) will be archived by Dr. Veronica Lambert.

- Any personal details recorded during the interview process pertaining to you and your child such as demographic information or signed consent forms will be stored in a separate file to the audio recordings.

- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.

- The information we collect from all the families who take part will be used to write a report on the findings and I will write my thesis using information we gather from families involved in this research. The MRCG (Medical Research Charities Group) and HRB (Health Research Board) who are funding the project will receive annual reports and the findings from the study may be published in journals whereby direct quotes from the interviews may be used in the write up. However, no information that might identify you or your family will be used.

- Anything you and your child/children say to us will be kept private between the research team and your family. We will only break this privacy if there is a concern for a child's safety. In this situation, we are obliged to bring this to the attention of staff in Temple Street, Children's University Hospital/Epilepsy Ireland. You and your child/children will be made aware of this need should the situation arise.

How will this study be of benefit to me and my children?

While there may be no immediate benefits to you, and your child/children from taking part in the study, the researchers hope that studies such as this one can be used to identify the needs of children living with epilepsy and thus inform and develop new services for families who have a child with a chronic illness. It is an opportunity for you and your child/children to share your experience with others.

Are there any risks or downsides to taking part?

- There is a chance that while you or your child/ children are talking about your experiences, you or your child/children may feel upset. If you or your child/children become upset when talking to me, we will ask you and your child/children if you want to stop, take a break or, for child interviews, if they would like to have a parent sit with them to make them feel more comfortable. We will let you know if your child becomes upset at any stage.

- After the study, if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your local Community Resource Officer in Epilepsy Ireland) who can advise you on next steps.

What if I, or my child, change their mind?

- If you and your child/children agree to take part but later change your minds, all you have to do is let me know by a phone call or email. You do not have to give a reason for withdrawing and withdrawing from the study will in *no way* affect your involvement in Epilepsy Ireland/Temple Street Children's University Hospital.

Is there anything else I need to know?

- If you would like to talk informally with me about any questions or queries you may have about this research, my contact details are below.

You can contact me with any questions you have about this research by calling me on 01-7006867 or emailing stephanie.otoole29@mail.dcu.ie. I would be more than happy to address any concerns that you may have.

Additionally, you can contact my supervisor, Dr. Veronica Lambert, at veronica.lambert@dcu.ie.

If participants have concerns about this study and wish to contact an independent person, please contact: *The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000*

Appendix C5: Child Information Sheet (Phase One)

Would you like to help me with my project?

Families talking about epilepsy

My name is Stephanie, and I'm doing a project on what it is like to talk to your family about epilepsy.... If you want, you can help me!

What will I do in the project?

I will come to talk to you about what it is like having epilepsy and how your family help you. To help tell me all about your story you can draw pictures.

Don't worry, it will be fun!

Where will we meet?

I will come to your house to chat to you, or wherever your parents choose.

How long will it take?

Not too long, about half an hour.

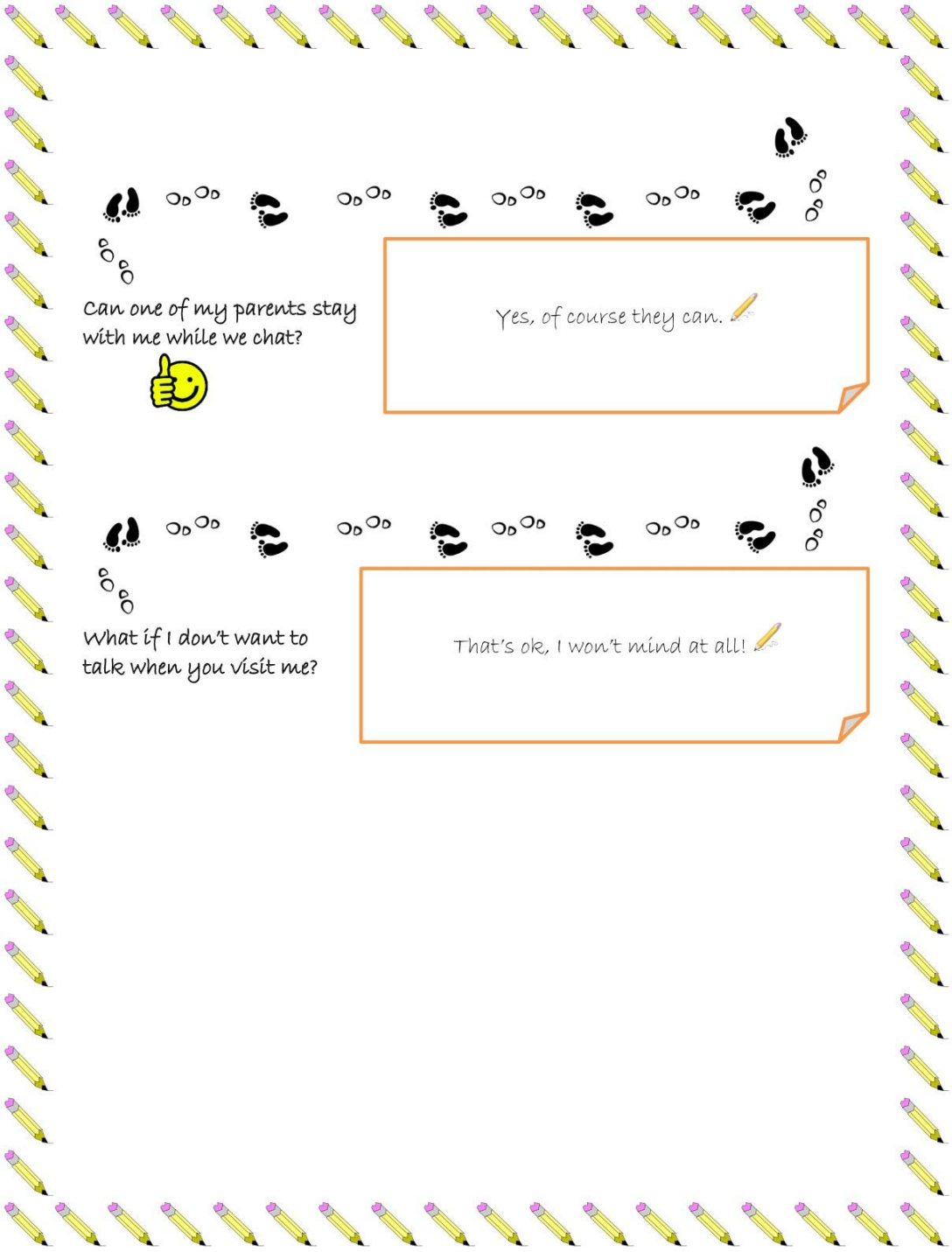
Why do I want your help?

I want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy, and how you and your family talk about those things.

What will happen to my answers and drawings?

I will be writing a big essay about what you and other children tell me, but don't worry, I won't write your name in the essay. There are no right or wrong things to say or draw – I'm just interested in hearing your story!

Appendix C5: Child Information Sheet (Phase One) (continued)



Appendix C5: Child Information Sheet (Phase One) (continued)

My name is Stephanie O' Toole and I am a student at Dublin City University...

My phone number is 01-7006867 and my email address is stephanie.otoole29@mail.dcu.ie

If you have any questions, just ask your parents if you can contact me – I'm very happy to answer any questions you might have.

Appendix C6: Young-Person Information Sheet (Phase One)

Would you like to help me with my project?

Families talking about epilepsy

My name is Stephanie, and I'm doing a project on what it is like to talk to your family about epilepsy.

What will I do in the project?

I would like to come and chat to you about what it is like to have epilepsy and how your family help you. You can draw pictures to help tell me about your story.

To make sure I don't forget anything important that you tell me – I will record our chat on my iPod.

Where will we meet?

I will come to your house to talk to you, or wherever your parents choose.

How long will it take?

That depends on how much you have to say, but probably about 45 minutes.

Why do I want this information?

I want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy, and how you and your family talk about those things

What will happen to my answers?

I will be writing a long essay about what you and other young people tell me – but don't worry, I won't mention your name in the essay! There are no right or wrong things to say, I'm just really interested in your story.

Your answers will be locked away in a safe place so that no one else can see them.

Can one of my parents stay with me while we chat?

Yes, of course they can.

What if I don't want to talk when you visit me?

That's ok, I won't mind at all!

My name is Stephanie O' Toole and I am a student at Dublin City University...

My phone number is 01-7006867 and my email address is stephanie.otoole29@mail.dcu.ie

If you have any questions you want to ask me before I visit you, just ask your parents if you can contact me –
I'm very happy to answer any questions you might have.

Appendix C7: Recruitment Advertisement (Phase One)

Research Study: Families talking about Epilepsy

Call for Research Participants.

Research volunteers are currently being sought for a study developed by Epilepsy Ireland, in conjunction with Temple Street Children's University Hospital and DCU. The research study aims to investigate how families talk about epilepsy and related issues. We are interested in finding out the challenges faced by families of children with epilepsy and you and your child's experiences of living with epilepsy. We are particularly interested in hearing about you and your child's experiences of talking/not talking about epilepsy and the impact of your discussions on your opinions of epilepsy as a condition.

What does participating in the study involve?

We would like to have an opportunity to speak with parents and any children in their family who are between 6 and 15 years of age and who have been diagnosed with epilepsy for more than 6 months. We will speak to you about how you live with epilepsy as a family and what issues you face when talking about the condition in a family environment.

How can I get involved?

If you or your child would like to hear more about this research study, please contact Stephanie O' Toole on 01-7006867 or, email stephanie.otoole29@mail.dcu.ie, for further information. We look forward to hearing from you!

Appendix D: Interview Protocols

Appendix D1: CWE Interview Protocol

Child showing signs of upset/anxiety/tiredness

Due to the nature of the project it is unlikely any harm will be caused to the child participants. However, it is appreciated that they may become upset or anxious if the discussions require the recall of parent/child dialogue surrounding the sensitive topic of epilepsy related stigma. Before undertaking an interview the researcher will verify with the parents and child that he/she is in full health. Nevertheless, the researcher is conscious that, as the participants have a chronic illness, they may show signs of tiredness, feel unwell, or have a seizure during the interview.

Should any child show signs of upset/anxiety/tiredness the following steps will be taken:

- The researcher will be continuously alert for any signs of unforeseen events i.e. anxious/upset/tired/unwell child
- At the outset of the interview the researcher will agree a hand signal that the child can use to halt the interview
- Should any child become upset or tired their participation in the interview will be stopped and they will be offered the opportunity to either; take a break, reschedule or withdraw from the study.
- Reassurance and comfort will be given to the child by the researcher and the child's parent(s), if not already in attendance at the interview, will be informed immediately and the child will be reunited with their family.
- Once ready, the researcher will return to talk with the child and his/her parent to ensure that they understand that halting the interview or withdrawing from the study will have no impact on any future care the child may require in the hospital.
- With the agreement of a parent, if the child wishes to continue their involvement with the study another opportunity to be interviewed will be offered. If the opportunity to participate further is declined, the child will be thanked for his/her contribution to the project.

Child becoming unwell or having a seizure

Due to the chronic nature of the epilepsy condition the prospective child participants live with it is possible that children may become unwell or have a seizure during the interview.

Should any child become unwell or have a seizure, the following steps will be taken:

- The interview will be immediately halted and if the parent of the child has not stayed in the room during the interview they will be called in straight away.
- The researcher will stay with the child and make sure that he/she is ok until the parent comes into the room. If necessary, appropriate first aid actions will be taken according to the official guidelines from Epilepsy Ireland. These guidelines state; to allow the seizure to run its course, to remain with the child until the seizure has stopped, to protect them from any real or potential danger (i.e. – by removing any potentially hazardous objects from the area or to cushion their head), to stay with them once recovery is complete and to reassure them and explain what has happened. Depending on the severity of the seizure, it may be necessary to gently place the child in the recovery position once the seizure has finished. If a seizure continues for more than five minutes, the emergency services will be called.
- The researcher will ensure that the parent and child are ok before leaving.
- If the child/parent still wishes to participate at a later date, the researcher will call the family to reschedule.
- If the child/parent does not wish to participate thereafter, the researcher will thank them for their time.

Child Protection Issues

It will be stressed at the outset of the study to parents and children that absolute confidentiality cannot be guaranteed. This is when child protection issues arise. If the child discloses any information that she/he or anyone else is at risk (i.e. abusive behaviour) the researcher is obliged under the Children First: National Guidelines for the Protection and Welfare of Children (Department of Children and Youth Affairs, 2011) to safeguard the welfare of the child regardless of the effect this will have on the study.

In accordance with the Department of Children and Youth Affairs Children's First document (2011) should a child disclose issues relating to safety, the below protocol will be observed:

- "(Name of child), you've told me that (E.g. someone is hurting you). This is something that I can't keep private between us; I need to tell, so that someone can help you. You are very brave to have told me though. I have to tell (Name of designated person in TSCUH/Epilepsy Ireland) about this so that she/he can arrange things, so that you can be helped."
- Gently end the interview, ensuring the child is not distressed or allowing him/her time to recover if he/she is distressed.
- Depending on the nature of the disclosure, the researcher will make a judgement, based on the best interests of the child, whether or not to inform the parent(s) of this disclosure.
- Agreed staff member at TSCUH/Epilepsy Ireland is informed of disclosure as soon as is possible (preferably immediately). Any concern of abuse, etc., will be reported to the on-duty social worker of the appropriate health board.
- Outside of normal hours, or if there is a serious threat to the child or other children, the Gardai will be informed immediately
- Information will be accurately recorded using templates from the National Guidelines for reporting such allegations.

Appendix D2: Parent Interview Protocol

Parent showing signs of upset/anxiety/tiredness

Should any parent show signs of upset/anxiety/tiredness the following steps will be taken:

- The researcher will be continuously alert for any signs of unforeseen events i.e. anxious/upset.
- Should any parent become upset their participation in the consultation workshop will be stopped and they will be offered the opportunity to either; take a break, reschedule or withdraw from the study.
- The researcher will talk with the parent to ensure that they understand that halting the interview or withdrawing from the study will have no impact on any future care their child may require in the hospital.
- If the parent wishes to continue their involvement with the study another opportunity to be interviewed will be offered. If the opportunity to participate further is declined, the parent will be thanked for his/her contribution to the project.

Appendix E: Interview Schedules

Appendix E1: Parent Interview Schedule

Topic Guide	Prompts
Tell me about your experience of your child's diagnosis.	*a) First seizure (when, where, how, feeling, etc.)* *b) Talking to Neurologist (when, where, feeling, etc.)* *c) Child's reaction to his/her first seizure* *d) Your reaction to your child's first seizure*
Tell me what it has been like for you to learn about epilepsy since your child's diagnosis.	*a) Did you find information about epilepsy easy to obtain?* *b) Did you find it helpful to talk to other parents of children with epilepsy?* *c) Are there any particular resources you found most helpful in learning about epilepsy?* *d) Do you feel there is still more you could learn about epilepsy?*
Tell me what it is like for your child to live with epilepsy every day?	*a) Seizures (frequency, when, where, feeling, etc.)* *b) Medications (when, where, how, etc.)* *c) School (seizures in school, absences from school, etc.)* *d) Attending hospital/clinic appointments* *e) Meeting friends* *f) Being able to participate or not participate in different things*
Tell me what it is like for your family to live with epilepsy every day?	*a) Talking about epilepsy* *b) Situations that arise due to epilepsy*
Tell me about what it is like for you to talk to your child about his/her epilepsy.	*a) Who, what, why, how, when does he/she talk to you about his/her epilepsy?* *b) What kind of language do you use when talking to your child about epilepsy?* *c) What does he/she find challenging/unchallenging to talk to you about?* *d) What things enable/prevent him/her talking to you about his/her epilepsy?* *e) What are the kinds of things that he/she does not mind telling you about his/her epilepsy?* *f) What things bother him/her most about talking to you about his/her epilepsy?* *g) Does your child find it helpful to talk to you about his/her epilepsy?* *h) Does talking to you about his/her epilepsy help your child to deal with certain situations?*
Tell me about what it is like for any other family member (e.g. parent, brothers/sisters, granny/granddad, etc.), living in your household, to talk to your child about his/her epilepsy.	*a) Who, what, why, how, when does he/she talk to them about his/her epilepsy?* *b) What does he/she find challenging/unchallenging to talk to them about?* *c) What things enable/prevent him/her talking to them about his/her epilepsy?* *d) What are the kinds of things that he/she does not mind telling them about his/her epilepsy?* *e) What things bother him/her most about talking to them about his/her epilepsy?* *f) Is there anyone in particular that your child finds it helpful to talk to about his/her epilepsy?*
Are there any aspects of your child's epilepsy that he/she would not talk to you or any other family members about?	*a) Can you tell me more about these things?* *b) What do you think makes it hard for him/her to talk about these aspects of his/her epilepsy?* *c) Why do you think your child would not like to talk to you about these things?*

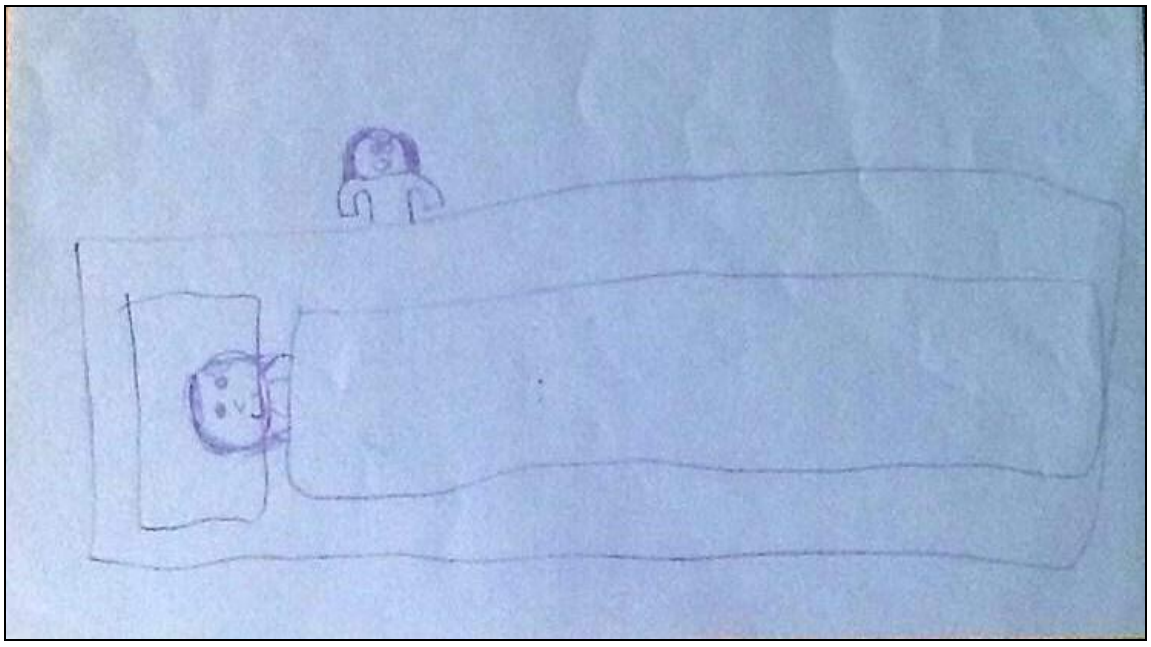
Appendix E1: Parent Interview Schedule (continued)

Topic Guide	Prompts
Are there things you would rather not talk to your child about, related to epilepsy?	*a) Can you think of a time when you found it difficult to talk to your child about epilepsy?* *b) Can you tell me more about this time?* *c) What do you think made it difficult to talk to your child about epilepsy?*
Tell me about what it is like for you to talk to other people about your child's epilepsy.	*a) Who, what, why, how, when do you talk to other people about your child's epilepsy?* *b) What do you find challenging/unchallenging about talking to other people about your child's epilepsy?* *c) What things bother you most about talking to other people about your child's epilepsy?* *d) Do you think that other people view your child as different because of his/her epilepsy?* *e) Do you think there is a negative stigma attached to your child's epilepsy?*

Appendix E2: Child/Young-Person Interview Schedule

Topic Guide	**Prompts**
Tell me what it is like for you to live with epilepsy every day?	*a) Seizures (frequency, when, where, feeling, etc.)* *b) Medications (when, where, how, etc.)* *c) School (seizures in school, absences from school, etc.)* *d) Attending hospital/clinic appointments* *e) Meeting friends* *f) Being able to participate or not participate in different things*
Tell me what it is like when you talk to your family (e.g. parents, etc.) about your epilepsy?	*a) Who, what, why, how, how often, when do you usually talk to your family about your epilepsy?* *b) What is good/not so good about talking to your family about epilepsy?* *c) What things help/stop you talking to your family about your epilepsy?* *d) What parts of your epilepsy do you find easy to talk to your family about?* *e) What things bother you most about talking to your family about your epilepsy?*
Can you tell me a story about a time when you talked to your parent(s) /Mum/Dad about your epilepsy?	*a) What did you talk about? Can you give me an example of when this happened?* *b) What did they say? Can you give me an example of when this happened?* *c) How did this make you feel?*
Are there times when you would not talk to your family about your epilepsy?	*a) Can you think of a time when you did not talk to your family about your epilepsy?* *b) Can you tell me more about this time?* *c) What made you decide not to talk to your parent(s)/Mum/Dad about this?* *d) Why would you not to talk to your parent(s)/Mum/Dad about this?*
Creative Interviewing	
Instructions	**Prompts**
Design a picture/collage about living with epilepsy and/or about what happens when you talk to your family (e.g. parents, etc.) about your epilepsy.	*a) Tell me about your design? What were you thinking about when you drew this picture/made this collage.* *b) What is going on in this picture/collage?* *c) What are the people in the picture/collage doing?* *d) What are the people in the picture/collage saying?* *e) How do the people in this drawing/collage feel?* *f) If the people in the drawing/collage could speak, what would they say?* *g) What title/name would you give this picture/collage?* h) *Is there anything that is missing from this drawing/collage?*

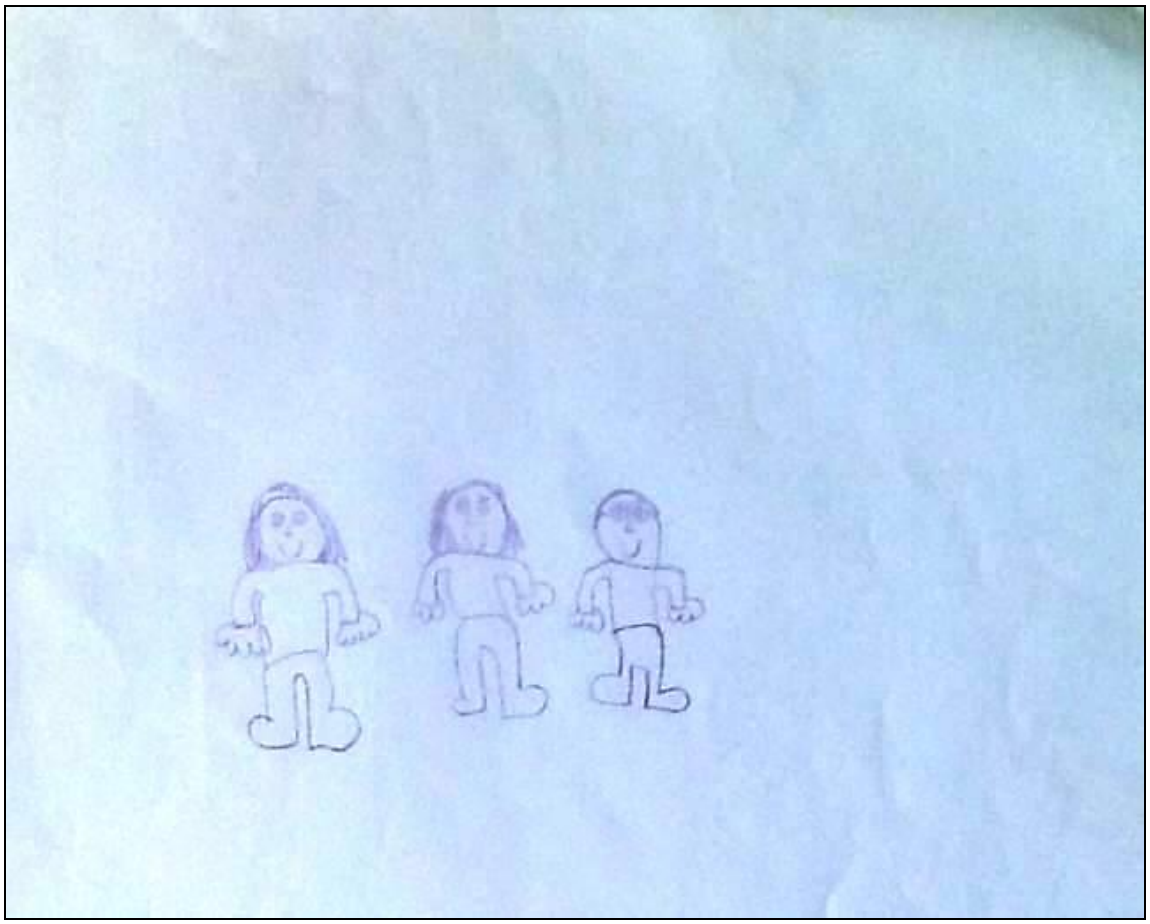
Appendix F: Creative Drawing



"This is me and there's my mum… Like I'm saying it doesn't feel good and she says it'll get better "

Taylor (female aged 10 years)

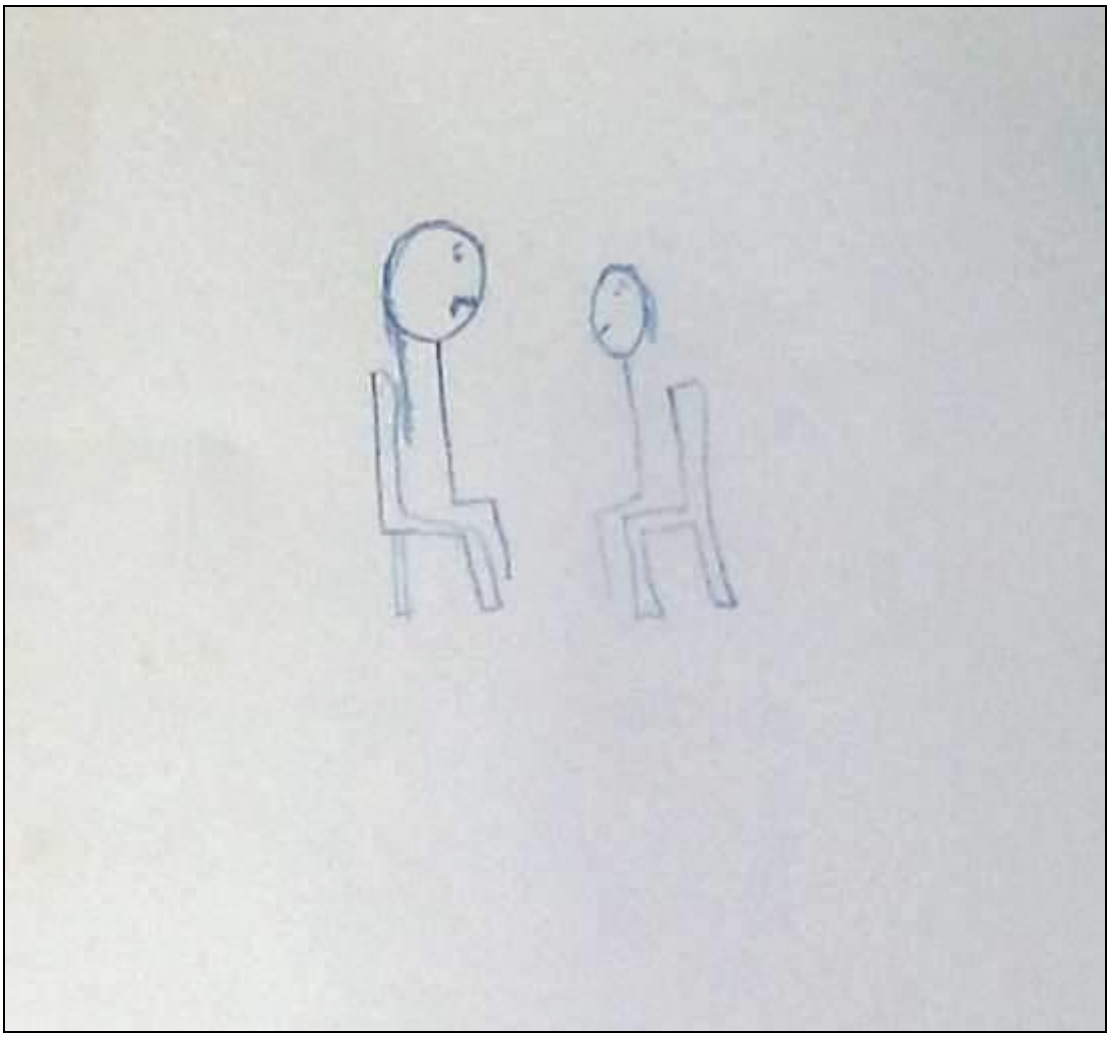
Appendix F: Creative Drawing *(continued)*



"That's my mum and that's me… I'm going to the hospital"

Taylor (female aged 10 years)

Appendix F: Creative Drawing *(continued)*



"Well me and my mother are just talking about it… em, just the time it happened 'cause I might tell her the next day like… 'cause, em, like the faster you tell someone like if you tell them you had one straight away they'd say right and they'd tell the doctors as soon as they could, you know"

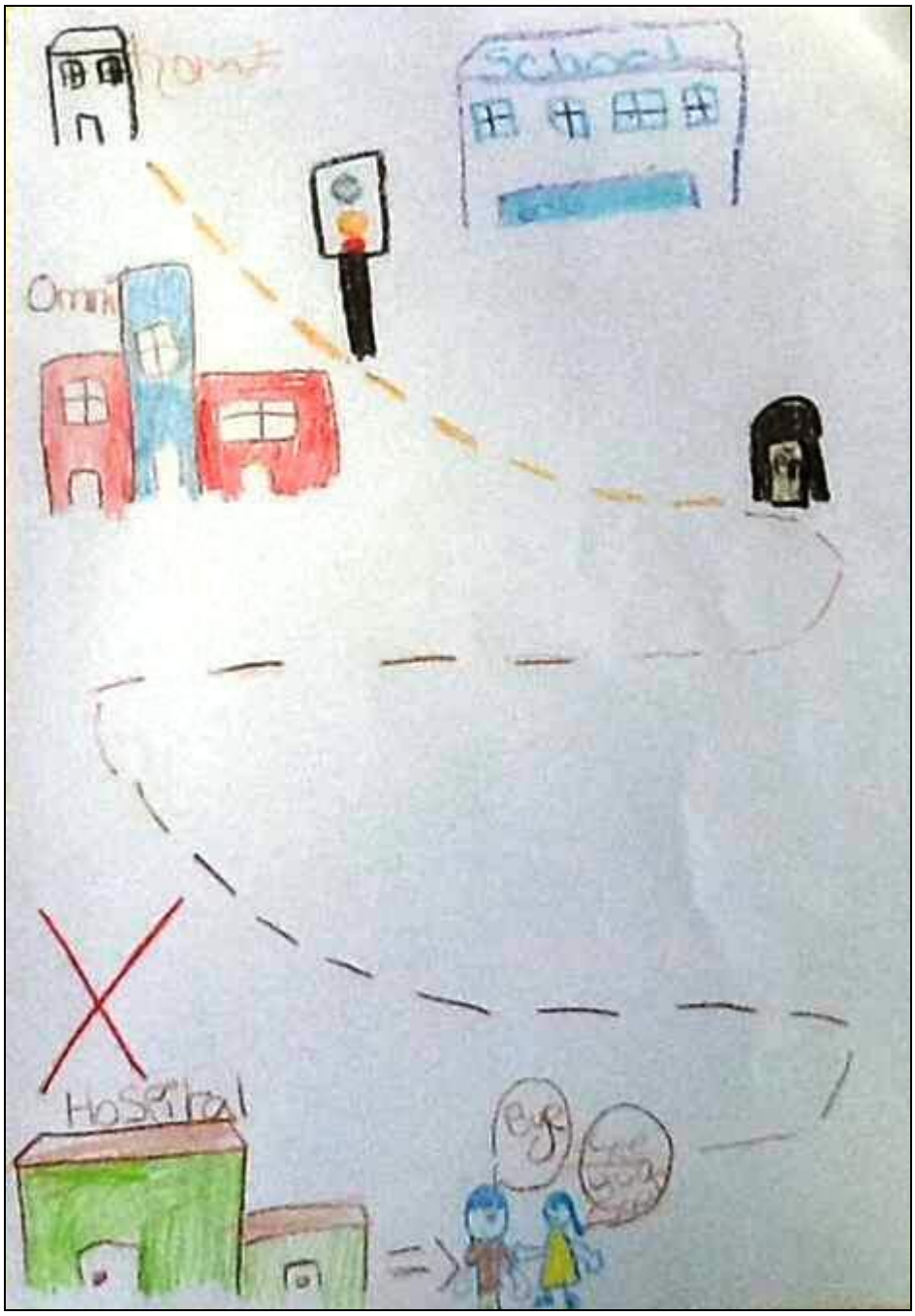
Ruth (female aged 13 years)

Appendix F: Creative Drawing *(continued)*

"I'm going to draw the stages … My Dad's having tea… I don't know what to say to them about epilepsy… I say 'Can I talk to you?', they say 'yes'. 'What's happening tomorrow for the doctors?', 'we can go in at nine O' clock and we can talk about things and see what happens next'… It makes me less confused and makes me feel better"

Selena (female aged 11 years)

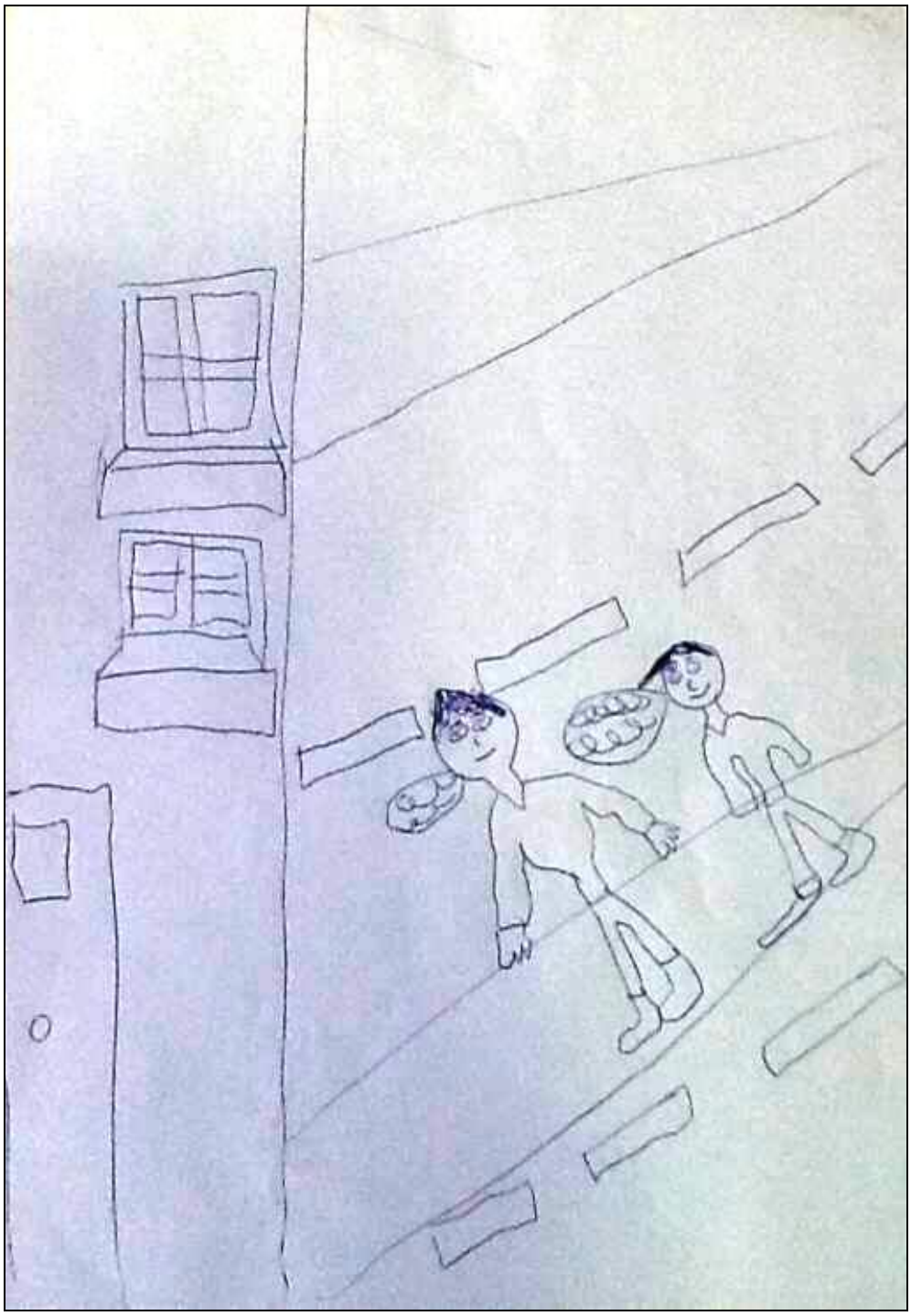
Appendix F: Creative Drawing *(continued)*



"A map of going to the hospital and then the doctor… the journey to it… the spot of the hospital 'cause it's in a map"

Selena (female aged 11 years)

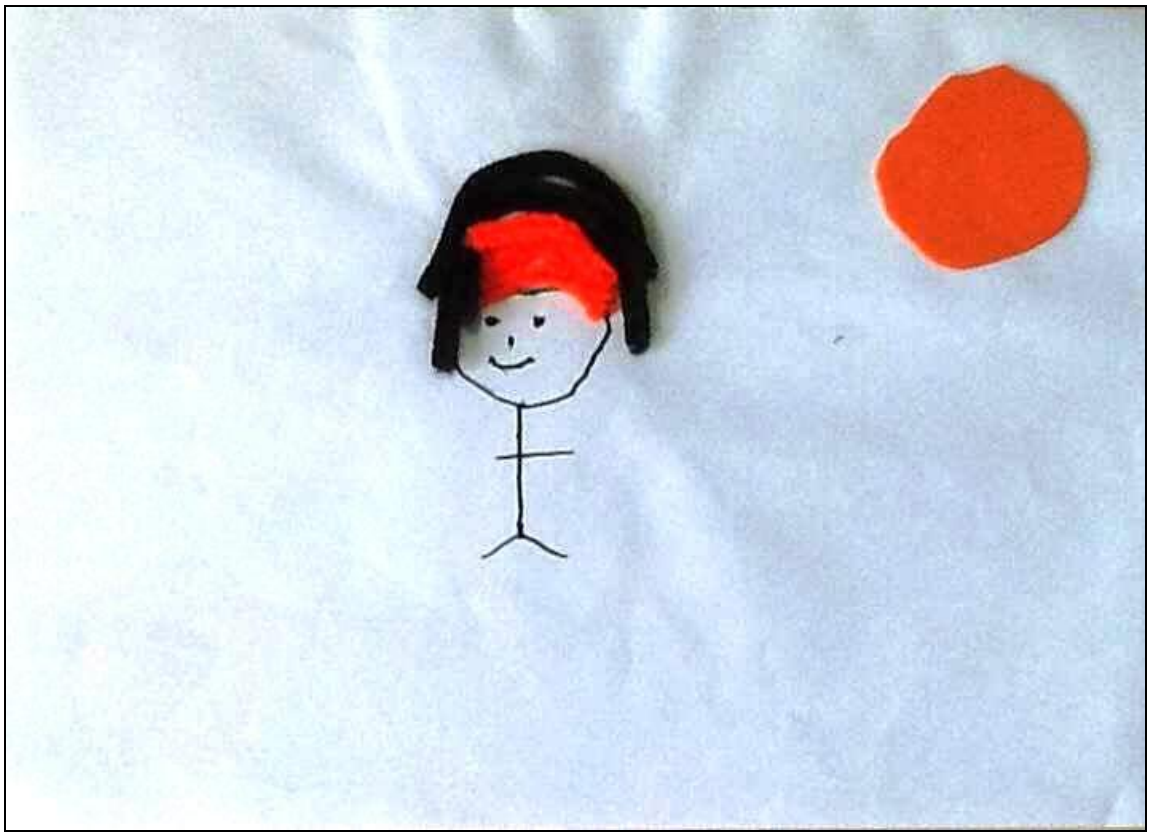
Appendix F: Creative Drawing *(continued)*



"Just me and my Mum on the way, me and my Dad actually cause I can't do women's hair very good on a drawing so, and just speech bubbles coming out and like squiggly lines"

Ryan (male aged 9 years)

Appendix F: Creative Drawing *(continued)*



Mandz (female aged 6 years)

Appendix F: Creative Drawing *(continued)*

Mandz (female aged 6 years)

Appendix F: Creative Drawing *(continued)*

"Em, living with epilepsy… well I was walking and then my leg went and then I fell, em, outside… and then my leg jumps... It makes me kind of feel like weak and stuff"

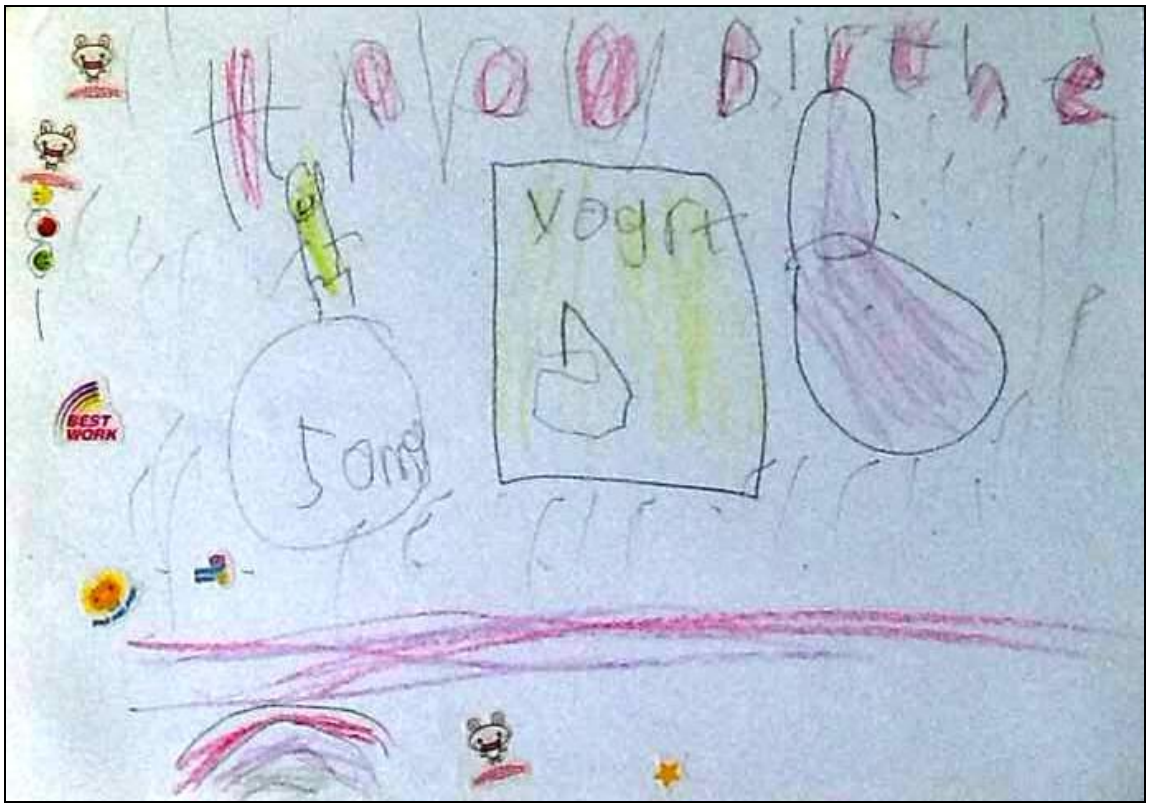
Lucy (female aged 7 years)

Appendix F: Creative Drawing *(continued)*

"Can I do like speech bubbles? Ok, I need to draw them big because like… How do you spell 'epilepsy'? I'm going to draw my Mum and Dad now… Yeah, that's my Mum but I have to draw her eyes and ears and mouth and nose… I'm drawing my Mum's big red dress"

Robyn (female aged 10 years)

Appendix F: Creative Drawing *(continued)*



"No, I will draw a picture of my yoghurt and my tablet… well I can't really do it good… That's the strawberry, this is the tablet… But I don't remember, what's the number called on my tablet? Fifty mg"

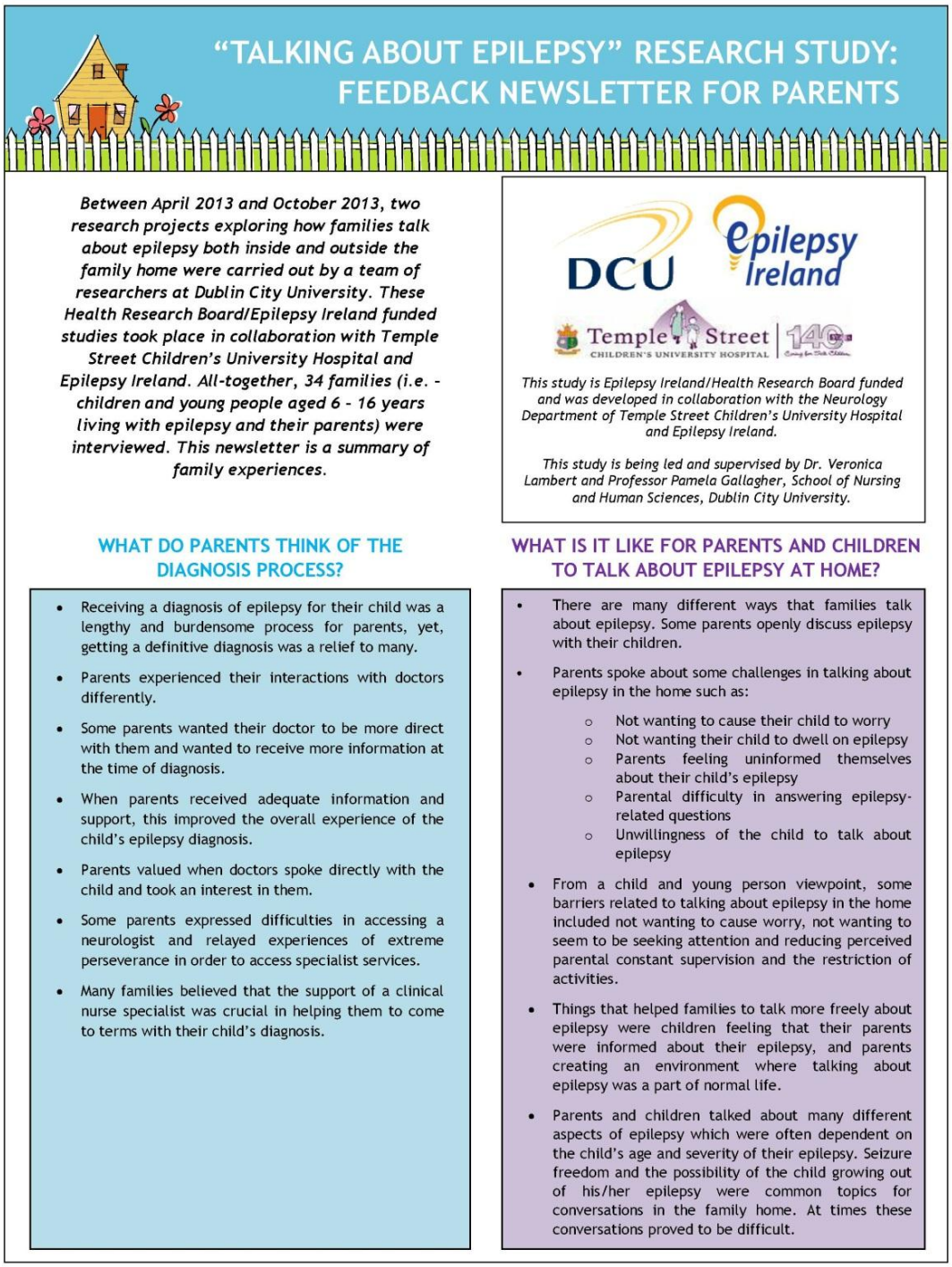
Elvis (male aged 7 years)

Appendix F: Creative Drawing *(continued)*

"Will I draw a picture of me having a seizure? This is just like a picture of me in my bedroom having a seizure"

Jessie (female aged 11 years)

Appendix G: Participant Feedback



"TALKING ABOUT EPILEPSY" RESEARCH STUDY: FEEDBACK NEWSLETTER FOR PARENTS

Between April 2013 and October 2013, two research projects exploring how families talk about epilepsy both inside and outside the family home were carried out by a team of researchers at Dublin City University. These Health Research Board/Epilepsy Ireland funded studies took place in collaboration with Temple Street Children's University Hospital and Epilepsy Ireland. All-together, 34 families (i.e. - children and young people aged 6 - 16 years living with epilepsy and their parents) were interviewed. This newsletter is a summary of family experiences.

DCU Epilepsy Ireland Temple Street Children's University Hospital 140

This study is Epilepsy Ireland/Health Research Board funded and was developed in collaboration with the Neurology Department of Temple Street Children's University Hospital and Epilepsy Ireland.

This study is being led and supervised by Dr. Veronica Lambert and Professor Pamela Gallagher, School of Nursing and Human Sciences, Dublin City University.

WHAT DO PARENTS THINK OF THE DIAGNOSIS PROCESS?

- Receiving a diagnosis of epilepsy for their child was a lengthy and burdensome process for parents, yet, getting a definitive diagnosis was a relief to many.
- Parents experienced their interactions with doctors differently.
- Some parents wanted their doctor to be more direct with them and wanted to receive more information at the time of diagnosis.
- When parents received adequate information and support, this improved the overall experience of the child's epilepsy diagnosis.
- Parents valued when doctors spoke directly with the child and took an interest in them.
- Some parents expressed difficulties in accessing a neurologist and relayed experiences of extreme perseverance in order to access specialist services.
- Many families believed that the support of a clinical nurse specialist was crucial in helping them to come to terms with their child's diagnosis.

WHAT IS IT LIKE FOR PARENTS AND CHILDREN TO TALK ABOUT EPILEPSY AT HOME?

- There are many different ways that families talk about epilepsy. Some parents openly discuss epilepsy with their children.
- Parents spoke about some challenges in talking about epilepsy in the home such as:
  - Not wanting to cause their child to worry
  - Not wanting their child to dwell on epilepsy
  - Parents feeling uninformed themselves about their child's epilepsy
  - Parental difficulty in answering epilepsy-related questions
  - Unwillingness of the child to talk about epilepsy
- From a child and young person viewpoint, some barriers related to talking about epilepsy in the home included not wanting to cause worry, not wanting to seem to be seeking attention and reducing perceived parental constant supervision and the restriction of activities.
- Things that helped families to talk more freely about epilepsy were children feeling that their parents were informed about their epilepsy, and parents creating an environment where talking about epilepsy was a part of normal life.
- Parents and children talked about many different aspects of epilepsy which were often dependent on the child's age and severity of their epilepsy. Seizure freedom and the possibility of the child growing out of his/her epilepsy were common topics for conversations in the family home. At times these conversations proved to be difficult.

Appendix G: Participant Feedback *(continued)*

WHAT IS IT LIKE FOR CHILDREN/YOUNG PEOPLE AND THEIR PARENTS TO LIVE WITH EPILEPSY EVERY DAY?

- Families thought about epilepsy in many different ways. Many families compared their child's epilepsy to other conditions which they thought might be worse. This helped them to cope and to see epilepsy as a manageable condition. Other families were very concerned about the diagnosis of epilepsy and thought it had more of a negative impact than other illnesses.
- Many parents did not let epilepsy restrict their child's activities. However, a number of children and young people reported awareness of restrictions imposed on them due to their epilepsy. In particular, parental desire for supervision of their child emerged as a common issue. Similarly, many teenagers talked about restrictions their peers imposed on them due to their epilepsy. Some of the main restrictions children and young people spoke about were related to sports, swimming, sleepovers, and discos. Teenagers also spoke about future restrictions they might encounter with driving, drinking alcohol and career choices.
- When asked about living with epilepsy, most of the children/young people and their parents spoke about medication. For some families, side-effects of medication presented an even greater challenge than seizures themselves. Many children/young people were worried about the fact that taking medication would expose their epilepsy diagnosis to their peers. Some parents worried about their child's adherence to medication and how not taking medication might affect seizure control.
- Parents and children/young people spoke about the effect of epilepsy on education and related issues, for example, tiredness, side effects related to taking medication such as concentration and memory difficulties, and poor attendance. Many parents spoke about working with their children at home to help them to keep up with their schoolwork.
- When informing the school about the child's epilepsy, some families relayed positive encounters. Many teachers were actively willing to learn about epilepsy and educate others (other teachers and students) about the condition.
- Other families relayed much less favourable stories about how some teachers and principal teachers had no desire to educate themselves and/or others about the epilepsy; this created some health and safety hazards. Parents felt some schools placed unnecessary restrictions on the child. This often made their child feel different and promoted social exclusion.
- The child's move from primary school to secondary school was a considerable source of stress for parents and presented a challenge for many families. In particular, state examination periods presented specific difficulties for a number of young people and parents.
- Some parents perceived support groups as particularly beneficial in coming to terms with their child's diagnosis of epilepsy. However, many parents expressed dismay at the lack of child-specific support groups available.

WHAT IS IT LIKE FOR PARENTS AND CHILDREN TO TELL OTHERS OUTSIDE THE IMMEDIATE FAMILY ABOUT THE CHILD'S EPILEPSY DIAGNOSIS?

- Parents and children/young people use different ways to talk to other people about epilepsy outside the family home; ranging from keeping the child's epilepsy a secret to being fully open and telling anyone and everyone about the child's epilepsy.
- Some parents and children/young people tell other people about the epilepsy diagnosis in the hope of reducing any epilepsy-related stigma and/or in case other people discover the child has epilepsy by witnessing seizures or medication taking.
- A number of families spoke about being selective about who they told and what aspects of the epilepsy they discussed with other people.
- Some reasons why parent did not tell others about their child's epilepsy were: 1) parents wanted a normal life for their child; 2) they saw epilepsy as a largely hidden condition; 3) they anticipated or had previous experiences of negative reactions when telling others; 4) they feared public perceptions of epilepsy; 5) they were coming to terms themselves with the diagnosis; and 6) parents were private in nature.
- Things that stopped children from telling other people about their epilepsy were: 1) anticipating or having previously experienced negative reactions when telling others; 2) feeling different; 3) the hidden nature of epilepsy; 4) difficulty understanding and explaining epilepsy to others; 5) children of similar age being unable to understand epilepsy; 6) children's own negative perceptions of epilepsy; 7) parental tendencies towards privacy; and 8) others' perceptions of epilepsy.

Appendix G: Participant Feedback *(continued)*

- While many families spoke about challenges related to telling other people outside the home about the epilepsy diagnosis, a number of families spoke about things that helped them to openly talk about epilepsy with others.
- Some of the things that helped parents to tell others about their child's epilepsy diagnosis included:
  - some seizure types (e.g. night-time and/or well-controlled epilepsy)
  - getting used to talking about and telling others about the child's epilepsy
  - positive reactions when telling others in the past about their child's epilepsy
  - good parental attitudes towards epilepsy
  - identifying with other parents whose children also feel different for some reason
  - improving public opinions about epilepsy
  - increasing feelings of safety for their child
- Some things that made it easier for children/young people to tell others about their epilepsy were:
  - thinking positively about their epilepsy
  - feelings of pride of having knowledge about epilepsy
  - parents normalising epilepsy
  - knowing and feeling informed about epilepsy
  - positive reactions when telling others in the past about their epilepsy
  - parents talking about epilepsy positively
  - identifying with other people who have something that makes them feel different too
  - positive portrayals of epilepsy in the media (in T.V. programmes/films, radio, online and in books/magazines etc.)

GOING FORWARD - WHAT COMES NEXT?

We have gained a lot of valuable information from our interviews with children/young people living with epilepsy and their parents, which we hope will go some way to inform the development of improved services for families living with epilepsy in the future. But, we still have much to learn. So, to add more strength to this work we are continuing on with this important project work in order to hear more about families experiences of talking about epilepsy inside and outside the home.

To hear more about your family experiences we have designed child/young person and parent SURVEY QUESTIONNAIRES which we are currently looking to test out with a number of families to make sure that they are understandable and to give us an idea as to how long they should take for families to complete. This will help us to make any appropriate changes before distributing the questionnaires to a larger population.

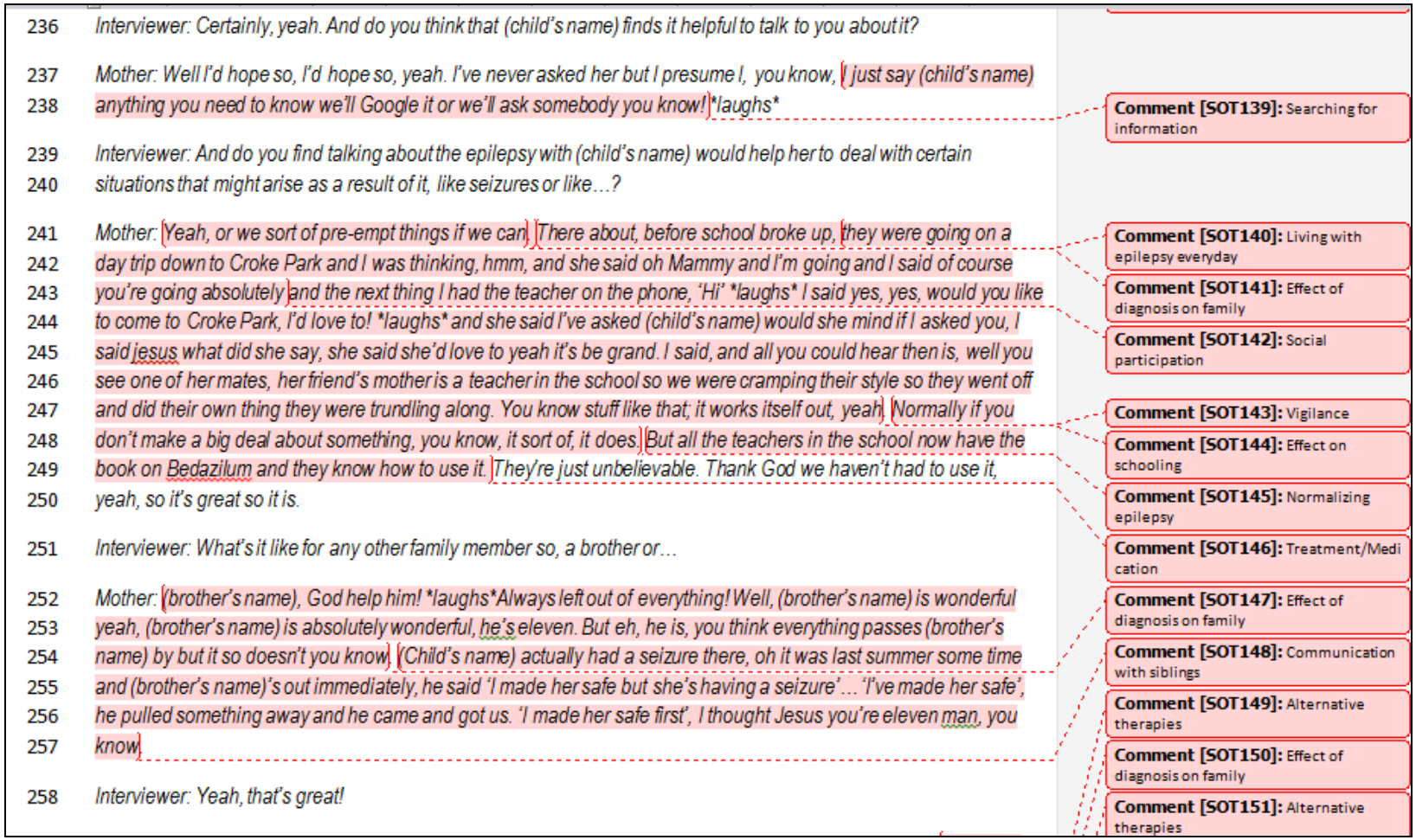
If you are interested in either getting involved in helping us to test out the questionnaires or in completing the survey questionnaires, please contact us at ailbhe.benson2@mail.dcu.ie or stephanie.otoole29@mail.dcu.ie. We would really appreciate any input you may be able to offer.

We would like to take this opportunity to thank you for your participation in this study. The information you have provided has been invaluable and we really appreciate your input. If you have any further queries please do not hesitate to contact us.

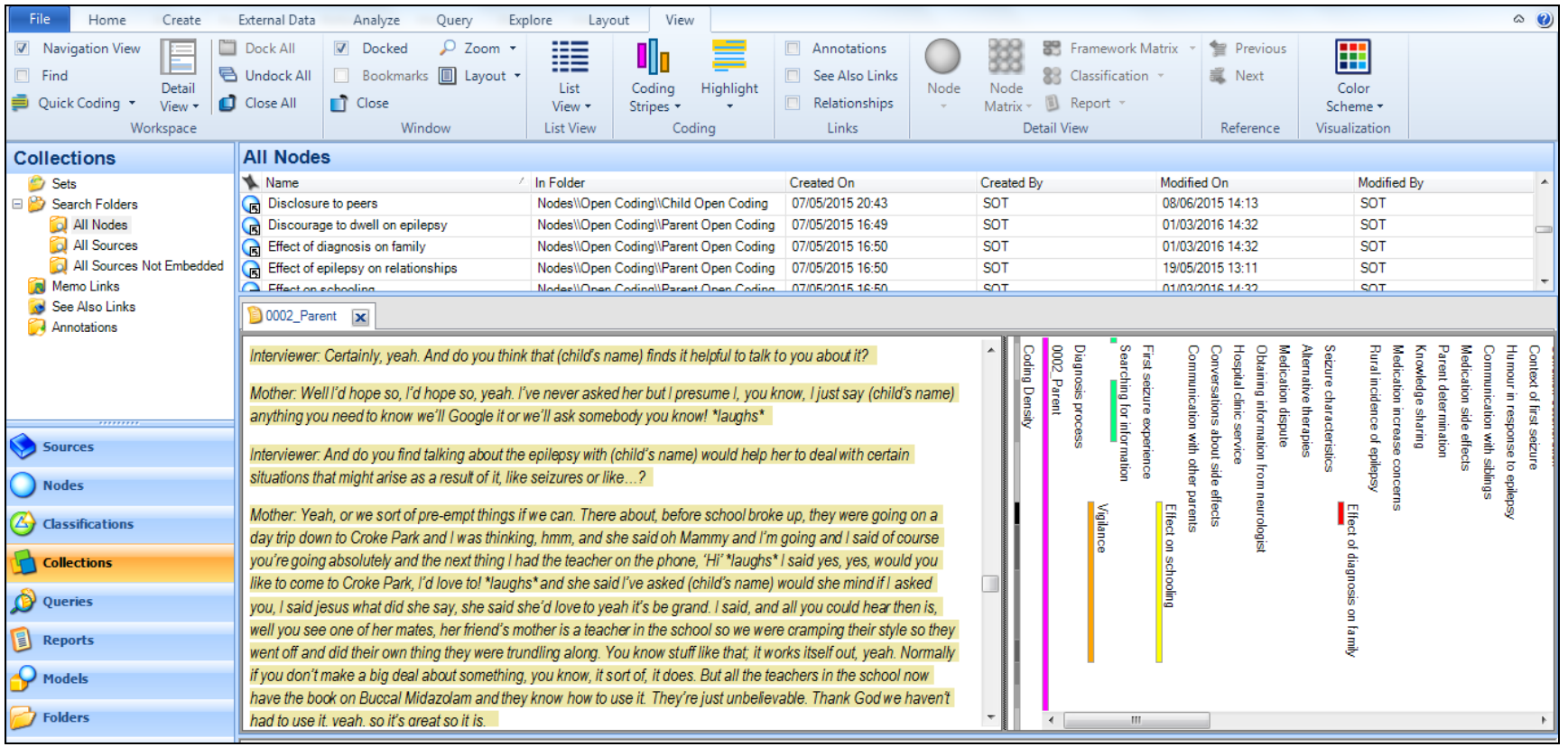
ailbhe.benson2@mail.dcu.ie *stephanie.otoole29@mail.dcu.ie*

Appendix H: Coding Samples

Appendix H1: Manual Coding Sample



Appendix H2: NVivo Coding Sample



Appendix I: Thematic Findings

Appendix I1: CWE Thematic Findings

CATEGORIES (5)	THEMES (22)	SUB-THEMES (55)	CODES (94)		
Diagnosis (3)	Epilepsy symptomatology	Symptomatology	Other medical conditions (72)		
		Seizure characteristics	Seizure characteristics (86)	Seizure description (87)	
			Seizure frequency (88)	Seizure triggers (89)	
		Epilepsy characteristics	Family history of epilepsy (46)	Condition improvement (25)	
	Learning about epilepsy at diagnosis	Reactions to diagnosis	Coming to terms with epilepsy (16)	Diagnosis process (35)	
		First seizure	Context of first seizure (26)		
		Communication at diagnosis	Epilepsy terminology (42)		
		Treatment	Alternative therapies (1)	Hospital/clinic service (52)	
		Problems	Less information is better (58)		
		Healthcare communication	Communication with doctors (20)		
	Understanding epilepsy	Need for information	Child need for information (12)		
		Information sources	Asking parents for information (2)		
		Benefits of understanding	Knowledge sharing (55)		
Family functioning (4)	Normalizing epilepsy	Avoiding "differentness"	Normalizing epilepsy (69)	Not wanting to draw attention (70)	
		Ways to normalize epilepsy	Condition comparison (24)		
	Invisibility of epilepsy	Ability to hide epilepsy	Concealing epilepsy (23)		
		Epilepsy becoming public	Fear of accidental disclosure (48)	Public seizures (82)	
	Impact of epilepsy on the child	Overall impact on child	Impact of epilepsy on child (53)		
		Child worry	Child worry (15)		
		Medication	Medication side effects (61)	Fatigue (47)	
		Impact on schooling	Dealings with school (34)	Effect on schooling (37)	Learning difficulties (56)
		Lifestyle change	Medication routine (60)		
	Impact of epilepsy on the family	Impact on parents	Parent worry (76)		
		Impact on relationships	Relationship with siblings (84)		
		Family functioning	Family circumstances (45)		
	Communication level related to seizure activity	Communication dependent on epilepsy-related events	Less communication with fewer seizures (57)		
	Child experiences of talking about epilepsy	Communication attitude	Child attitude towards family communication (4)		
		Communication experiences	Communication with siblings (22)	Creative data collection (33)	
		Communication advantages	Communication benefits (18)	Motivation for communication (63)	
			Parents viewed as understanding (75)		
		Communication disadvantages	Communication costs (19)		
		Communication consequences	Impact of parent-child communication on child (54)		

Appendix I1: CWE Thematic Findings (continued)

Family Communication (8)	**Epilepsy-related conversations**	Talking to/telling others	Conversations about disclosure (28)	Disclosure to peers (36)
		Treatment conversations	Conversations about hospital/clinic (29)	Conversations about medication (30)
		Symptomatology and how seizures appear	Conversations about seizures (31)	
			Conversations about what seizures look like (32)	
	Level of communication	Communication avoidance	Communication avoidance (17)	Minimal family communication (62)
			Reasons for communication avoidance (83)	
		Open communication	Open communication with parent (71)	
			No perceived barriers to communication (66)	No communication avoidance (65)
	Challenges to family communication	Communication challenges	"Awkward" conversations (3)	Perceived challenges to family communication (79)
			Epilepsy as an excuse (39)	No perceived challenges to family communication (67)
		Fear of parental worry	Child reassuring parent (13)	
		Communication barriers	Perceived barriers to family communication (78)	
		Conflict	Medication dispute (59)	
	Facilitators of family communication	Existence of communication facilitators	Perceived facilitators of family communication (80)	No perceived facilitators of family communication (68)
	Learning about epilepsy from parents	Explanatory conversations	Explaining epilepsy to child (43)	
		Reassurance in understanding	Parent reassuring child (73)	
	Context of family communication	Context of family communication	Context of parent child communication (27)	Who child communicates with (94)
			Frequency of parent-child communication (49)	
Child perspectives (4)	**Child attitude towards epilepsy**	Feelings towards epilepsy	Child feelings towards epilepsy (5)	Child feelings towards seizures (9)
		Feelings towards treatment	Child feelings towards hospital/clinic (6)	Child feelings towards medication (7)
	Vigilance	Self-vigilance	Child vigilance (14)	
		Parent vigilance	Parent vigilance (74)	Encouraging child autonomy (38)
	Restriction of Participation in Social Activities	Social participation	Social participation (91)	Sleepovers (90)
		Social restrictions	Child feelings towards restricted participation (8)	Child frustration (10)
			Restriction of social participation (85)	
	Child concerns for future	Growing out of epilepsy	Child knowledge of seizure-free period (11)	Getting epilepsy controlled (50)
			Growing out of epilepsy (51)	
External Communication (3)	**Communication with others external to family**	Peer/parent communication	Parents' communication with other parents (21)	Peer communication (77)
		Challenges outside family	External communication challenges (44)	
	Perceptions of Epilepsy	Portrayals of epilepsy	Public perceptions of epilepsy (81)	Epilepsy in media (40)
	Need for awareness	Public misinformation	Epilepsy stereotypes (41)	Need for awareness (64) / Support groups (92)
		Stigma	Teasing/Bullying (93)	

Appendix I2: Parent Thematic Findings

CATEGORIES (5)	THEMES (22)	SUB-THEMES (68)	CODES (152)
Diagnosis (3)	Epilepsy symptomatology	Parent-reported seizures	Seizure description (138)
		Seizure characteristics	Seizure characteristics (135) | Seizure triggers (140)
			Seizure frequency (139) | Period of seizure freedom (124)
		Specific diagnosis	Epilepsy type (63)
	Diagnosis process	Reactions to diagnosis	Child reaction to diagnosis (16) | Parent reaction to diagnosis (117)
		First seizure	First seizure exp. (172) | Context first seizure (32) | Context second seizure (34)
		Communication at diagnosis	Communication with others at diagnosis (23) | Disclosure at diagnosis (47)
		Treatment	Alternative therapies (1) | Diagnosis process (44) | Treatment/Medication (149)
		Problems	Disagreement with neurologist (46) | Misdiagnosis (97)
		Healthcare communication	Emergency service (55) | Hospital service (75) | Relationship with neurologist (130)
		Unpredictability	Other medical conditions (107) | Family history of epilepsy (68)
	Learning about epilepsy	Need for information	Child need for information (15) | Parent need for information (114)
			Parent need for specific information (115)
		Information sources	Communication with other parents (22) | Obtaining information (103)
			Obtaining information from neurologist (104) | Searching for information (134)
		Barriers to learning	Fear of the unknown (71) | Less information is better (87)
			Online information as misinforming (105) | Rural incidence of epilepsy (133)
		Advantages of understanding	Parent understanding of epilepsy (120) | Knowledge sharing (81)
Family functioning (5)	Normalizing epilepsy	Parent need to normalize	Normalizing epilepsy (100) | Parent determination (112)
		Way to normalize epilepsy	Removing reminders of epilepsy (131) | Humour in response to epilepsy (76)
	Invisibility of epilepsy	Ability to hide epilepsy	Invisibility of epilepsy (79) | Concealing epilepsy (26)
			Less communication with fewer seizures (86)
		Epilepsy becoming public	Public seizures (129) | Fear of accidental disclosure (69)
	Impact of epilepsy on the child	Impact on child	Behavioural difficulties (5) | Child disposition (12)
			Impact of epilepsy on child (78) | Comorbidities (25)
		Peer communication	Child communication with peers (10) | Disclosure to peers (50)
		Child worry	Child fear of disclosure (13) | Child worry (19)
			Not wanting to draw attention (102) | Teasing/Bullying (148)
		Attitude towards epilepsy	Child awareness of epilepsy (8) | Child determination (11)
			Child feelings towards epilepsy (14)
		Impact on schooling	Effect on schooling (54) | Dealings with school (42) | Learning difficulties (85)
		Lifestyle change	Medication routine (93)
	Impact of epilepsy on the parent	Attitudes towards epilepsy	Parent attitudes towards epilepsy (109) | Parent awareness of epilepsy (110)
			Not wanting to burden others (101)

Appendix I2: Parent Thematic Findings (continued)

		Future concerns	Parent concerns for future (111)		
		Impact on parent	Parent determination (112)	Parent frustration (113)	
			Parent stress (119)	Isolation (80)	
		Parent worry	Parent worry (121)	Fear of accidental disclosure (69)	
	Impact of epilepsy on the family	Impact at diagnosis	Effect of diagnosis on family (52)		
		Family functioning	Effect on relationships (53)	Communication with siblings (24)	Circumstances (67)
		Impact everyday	Living with epilepsy everyday (88)	Coming to terms with epilepsy (20)	
Family Communication (8)	**Communication level related to seizure activity**	"When there are no seizures it's almost like it's not there"	Less communication with fewer seizures (86)		
			Lack of communication not related to shame (82)		
	Communication avoidance	Parent perspectives	Avoidance to "not scare" child (3)	Parent reassuring child (118)	
		Child perspectives	Avoidance to "not scare" parent (4)	Child reassuring parent (17)	
	Challenging conversations about seizure-free period	Explaining seizure-free period to child	Conversations RE seizure free period (38)	Answering child's questions (2)	
			Child need for information (15)	Explaining epilepsy to child (64)	
		Challenges faced by parents	Child worry (19)	Fear of misinforming child (70)	Unpredictability of epilepsy (150)
		Controlling epilepsy	Grow out of it (73)	Getting epilepsy controlled (74)	Period of seizure freedom (124)
	Challenging conversations about appearance of seizures	Answering child's questions RE what seizures look like	Answering child's questions (2)	Avoidance of communication to "not scare" child (3)	
			Conversations about what seizures look like (40)	Child need for information (15)	
	Challenging conversations about medication side effects	Child need for information	Child need for information (15)		
		Restricting information	Avoidance of communication to "not scare" child (3)	Child worry (19)	
			Medication as risk-taking (89)	Med increase concerns (92)	
		Sources of conflict	Medication dispute (90)	Medication routine (93)	
		Side effects	Medication side effects (94)		
	Challenges to family communication	Recognised challenges	Answering child's questions (2)	Challenges to family communication (6)	
			Epilepsy as an excuse (59)	Presuming child will voice concerns (127)	
			Unpredictability of epilepsy (150)		
		Family understanding	Extended family's understanding (65)	Parent understanding of epilepsy (120)	
		Lack of communication	Lack of comm. Not related to shame (82)	Lack of communication related to age (83)	
			Minimal family communication (96)	Unwillingness to talk about epilepsy (151)	
		Future issues	Challenges yet to arise (7)		
		Barriers to communication	Avoidance to "not scare" child (3)	Avoidance to "not scare" parent (4)	
			Concealing epilepsy (26)	Disabling talk (45)	
			Discouraged to dwell on epilepsy (51)	Fear of misinforming child (70)	
			Possible stigma-coaching (125)		
		Facilitating communication	Humour in response to epilepsy (76)	Spontaneous communication (145)	
			Enabling communication (56)	Encouraging child autonomy (58)	
			Communication as coping mechanism (21)		

Appendix I2: Parent Thematic Findings (continued)

	Enablers of family communication	Family/child communication	Communication with siblings (24)		
			Child communication with other family members (9)		
		Parent/child communication	Open communication with parent (106)	Pre-empting child concerns (126)	
	Context of family communication	Context of family communication	Context of parent-child communication (33)	Spontaneous communication (145)	
			Less communication with fewer seizures (86)	Epilepsy terminology (62)	
Parent perspectives (4)	**Comparing epilepsy to other conditions**	Condition comparison	Condition comparison (downward) (28)	Condition comparison (upward) (29)	
			Condition comparison (27)		
		Seizure comparison	Seizure comparison (downward) (136)	Seizure comparison (upward) (137)	
	Parent need for information	Why parents seek information	Parent need for information (114)	Fear of misinforming child (70)	
			Fear of the unknown (71)	Knowledge sharing (81)	
		Attitudes towards epilepsy	Parent attitudes towards epilepsy (109)	Parent awareness of epilepsy (110)	
	Vigilance	Need for vigilance	Vigilance (152)	Disclosure on a need-to-know basis (49)	
		Hyper vigilance	Hyper-vigilance (77)	Parental over-protection (122)	
		Future vigilance concerns	Parent concerns for future (111)		
	Restriction of Participation in Social Activities	Social restrictions	Social participation (143)	Sleepovers (142)	
			Restriction of social participation (132)		
		Impact on child	Impact of epilepsy on child (78)	Isolation (80)	
		Conflict with "not wanting to be different"	Child determination (11)	Parent determination (112)	
			Not wanting to draw attention (102)		
Stigma (2)	**Public Perceptions of Epilepsy**	Public perceptions	Epilepsy in media (60)	Epilepsy stereotypes (61)	
			Public perceptions of epilepsy (128)	Public seizures (129)	
		Enacted stigma	Child treated differently (18)	Cultural stigma (41)	Encountering stigma (57)
		Felt stigma	No perceived stigma (99)	Perceived stigma (123)	Possible stigma-coach (125)
		Public comm. challenges	External communication challenges (66)	Invisibility of epilepsy (79)	
	Need for awareness	Public misinformation	Epilepsy in media (60)	Epilepsy stereotypes (61)	
		Stigma	Perceived stigma (123)		
		Support concerns	Social supports (144)	Support groups (147)	Lack of support available (84)

Appendix J: Participant Characteristics (Phase One)

Pseudonym	Gender	Age	School Class	Age at Diagnosis	Seizure Types	Time since last seizure	Treatment Path	Family History of Epilepsy	Epilepsy Terminology	Parent Interviewee
Taylor	Female	10	4th Class	8	• Tonic-Clonic *(primary)* • Partial	1 – 6 Months	Monotherapy	Yes (Cousin)	"Seizures"	Mother
Hermione	Female	13	1st Year	11	• Eyelid Myoclonia *(primary)* • Tonic-Clonic • Absence	Hours	Polytherapy	No	"Epilepsy/Seizures"	Mother
Dave	Male	12	6th Class	2	• Partial *(primary)* • Tonic-Clonic • ESES	1 – 6 Months	Polytherapy	No	"Epilepsy/Seizures"	Mother
Ruth	Female	13	6th Class	4	• Partial *(primary)* • Tonic-Clonic	Hours	Polytherapy	No	"Epilepsy/Seizures"	Mother
Marie	Female	13	1st Year	9	• Complex Partial *(primary)* • Absence • Partial	Weeks	Polytherapy	No	"Funny feelings"	Mother
Cee Lo	Female	8	1st Class	4	• Tonic-Clonic *(primary)* • Absence • Myoclonic	During Interview	Polytherapy	No	"Wobbly moments"	Mother
Selena	Female	11	5th Class	4	• Partial *(primary)* • Eyelid Myoclonia	Weeks	Polytherapy	Yes (Aunt)	"Frights"	Mother
Anna	Female	15	3rd Year	6	• Complex Partial	1 – 6 Months	Monotherapy	No	"Epilepsy/Seizures"	Mother
Nikki	Female	15	3rd Year	12	• Tonic-Clonic *(primary)* • Absence	Days	Polytherapy	Yes (Cousin)	"Seizures"	Mother
Tadhg	Male	12	6th Class	6	• Partial	Hours	Polytherapy/VNS	No	"Fizzies/Seizures"	Mother & Father
Rebecca	Female	15	3rd Year	12	• Absence	Days	Monotherapy	No	"Seizures"	Mother
Colm	Male	12	5th Class	8	• Partial	Hours	Polytherapy	No	"Seizures"	Mother

Pseudonym	Gender	Age	School Class	Age at Diagnosis	Seizure Types	Time since last seizure	Treatment Path	Family History of Epilepsy	Epilepsy Terminology	Parent Interviewee
Rooney	Male	10	4th Class	4	• Tonic *(primary)* • Tonic-Clonic	1 – 6 Months	Monotherapy	Yes (Aunt)	"Fits"	Mother
Ryan	Male	9	3rd Class	8	• Tonic-Clonic *(primary)* • Partial	Weeks	Monotherapy	No	"Seizures/Fits"	Mother
Mandz	Female	6	Senior Infants	4	• Absence	7 – 12 Months	Monotherapy	No	"Seizures"	Mother
Tony	Male	13	6th Class	6	• Tonic *(primary)* • Tonic-Clonic • Atonic	13 – 18 Months	Polytherapy	No	"Epilepsy/Seizures/ Pins and Needles"	Mother & Father
Lucy	Female	7	1st Class	7	• Atonic *(primary)* • Myoclonic • Absence	During Interview	Polytherapy	Yes (Unknown)	"Epilepsy"	Father
Audrey	Female	15	3rd Year	14	• Absence	7 – 12 Months	Monotherapy	No	"Absences"	Mother & Father
Macklemore	Female	14	1st Year	12	• Tonic-Clonic *(primary)* • Absence	Hours	Monotherapy	Yes (Grandmother)	"Epilepsy/Seizures"	Mother
Robyn	Female	10	3rd Class	9	• Absence	1 – 6 Months	Monotherapy	No	"Trances"	Mother & Father
Aoife	Female	16	4th Year	6	• Tonic-Clonic	1 – 6 Months	None Currently	Yes (Great Uncle)	"Epilepsy/Seizures"	Mother
Elvis	Male	7	2nd Class	2	• Tonic-Clonic *(primary)* • Absence • Atonic • Myoclonic	1 – 6 Months	Polytherapy	Yes (Uncle)	"Fits"	Mother

Pseudonym	Gender	Age	School Class	Age at Diagnosis	Seizure Types	Time since last seizure	Treatment Path	Family History of Epilepsy	Epilepsy Terminology	Parent Interviewee
Tom	Male	11	6th Class	6	• Absence	1 – 6 Months	Polytherapy	No	"Zoning out"	Mother
Sinead	Female	6	1st Class	3	• Tonic-Clonic *(primary)* • Partial	Days	Polytherapy	Yes (Sister)	"Epilepsy/Seizures"	Mother & Father
Eve	Female	12	6th Class	7	• Absence • Partial *(primary)* • Tonic-Clonic	Years	Monotherapy			
Kate	Female	8	2nd Class	5	• Partial (primary) • Tonic-Clonic • ESES	7 – 12 Months	Polytherapy	No	"Wibbly legs"	Mother
Paul	Male	13	2nd Year	10	• Complex Partial *(primary)* • Tonic-Clonic	Days	Polytherapy	No	"Epilepsy/Seizures"	Father
Michael	Male	15	3rd Year	14	• Tonic-Clonic	Weeks	Monotherapy	Yes (Father's Cousin)	"Epilepsy"	Mother
Jessie	Female	11	6th Class	8	• Tonic-Clonic (primary) • Absence	7 – 12 Months	Monotherapy	No	"Epilepsy/Seizures"	Mother

Appendix K: Ethical Approval (Phase Two)

Appendix K1: DCU Ethical Approval (Phase Two)

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Dr Veronica Lambert
School of Nursing and Human Sciences

10th September 2014

REC Reference:	**DCUREC/2014/191**
Proposal Title:	**Talking about epilepsy: A collaboration of two studies examining 1) family communication (study A); and 2) the selection of disclosure strategies (study B) in families living with epilepsy**
Applicants:	**Dr Veronica Lambert, Ms Stephanie O'Toole, Ms Ailbhe Benson, Professor Pamela Gallagher, Dr Amre Shahwan**

Dear Veronica,

Further to expedited review, the DCU Research Ethics Committee approves this research proposal. Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further submission should be made to the REC.

Yours sincerely,

DCU Research & Innovation

Dónal O'Mathúna

Dr. Donal O'Mathuna
Chairperson
DCU Research Ethics Committee

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
Baile Átha Cliath, Éire

Research & Innovation Support
Dublin City University,
Dublin 9, Ireland

T +353 1 700 8000
F +353 1 700 8002
E research@dcu.ie
www.dcu.ie

Appendix K2: TSCUH Ethical Approval (Phase Two)

Children's University Hospital
TEMPLE STREET, DUBLIN

DEPARTMENT OF RESEARCH
Children's University Hospital
Temple Street, Dublin 1
Tel: +353 1 892 1787
Email: research@cuh.ie Web: www.cuh.ie

Ms Ailbhe Benson
School of Nursing and Human Sciences
DCU
Glasnevin
Dublin 9

21st August 2014

Re: 14.026. Talking about epilepsy

Dear Ms Benson,

Thank you for your response to the Ethics Committee letter dated 18th July 2014. You have successfully addressed the concerns raised by the Committee and therefore the Committee is happy to grant ethics approval for your project.

We wish you every success with your study. The research Office would like to receive a report on completion.

Yours sincerely,

Prof Philip D Mayne
Medical Secretary Ethics Committee
MCRN: 06935

c.c. Department of Research

Appendix K3: Our Lady of Lourdes Ethical Approval (Phase Two)

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Regional Manager Consumer Affairs
HSE Dublin North East

Bective Street, Kells
Co. Meath

Tel: +353 (0) 46 9251264
Fax: +353 (0) 46 9251774

Loughtee Business Park
Drumalee, Cavan

Tel: +353 (0) 49 4377343
Fax: +353 (0) 49 4377379
Email: consumeraffairs.hsecne@hse.ie

9th April 2015

Ms Ailbhe Benson
School of Nursing and Human Sciences
Dublin City University
Glasnevin
Dublin 9

Re/ **"Talking about Epilepsy"**
Email correspondence from Ms Stephanie O'Toole dated 23/03/15

Dear Ms Benson

I am in receipt of correspondence from Ms Stephanie O'Toole dated 23rd March 2015 regarding an amendment to the above study.

I wish to advise that I have reviewed same and approval is given for the amendment to the study as outlined.

This will be formally noted at the next Research Ethics Committee meeting.

Yours sincerely

Dr Brendan MacMahon
Chairperson
HSE North East Area
Research Ethics Committee

Copied to/ **Dr Veronica Lambert, Lecturer, Nursing and Human Sciences, Dublin City University**
Ms Fiona Edwards, A/GM, Our Lady of Lourdes Hospital, Drogheda, Co Louth
Ms Emma Gordon, Lead Paediatrician, Our Lady of Lourdes Hospital, Drogheda, Co Louth
Dr Siobhan Gormally, Consultant Paediatrician and Neonatologist, Our Lady of Lourdes Hospital, Drogheda, Co Louth

Appendix K4: St. James' Ethical Approval (Phase Two)

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

THE ADELAIDE & MEATH HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND
TELEPHONE +353 1 4142000

Ms. Stephanie O'Toole
School of Nursing and Human Sciences
DCU
Glasnevin
Dublin 9

27th March 2015

RE: Talking about Epilepsy

REC Reference: 2015-03 Chairman's Action (20) ***Please quote REC reference on all correspondence***

Dear Ms. O'Toole,

Thank you for your correspondence dated 25th March to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above study.

The Chairman, on behalf of the SJH/AMNCH Research Ethics Committee has given ethical approval to this study.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

Appendix L: Recruitment Materials (Phase Two)

Appendix L1: Child/Young-Person Information Sheet (Phase Two)

Child/Young Person Information Sheet

Talking about epilepsy:
Would you like to help us with our project?

Our names are Ailbhe and Stephanie and we are students at Dublin City University. We are doing a project on what it is like for young people like you to have epilepsy

What will I do in the project?

We would like you to fill out a questionnaire about what it is like to have epilepsy. We will ask you about your epilepsy and what it is like for you to talk to your parents and people outside of your family, like your friends, teachers and neighbours, about your epilepsy.

How long will this all take?

Probably about 1 hour but you can take your time and you can take as many breaks as you want to. When you are filling out the questionnaire, it is fine if you decide you want to stop at any stage and you do not want to take part any more. Whether you want to take part or not is completely up to you.

Why do we want this information?

We want to know what are the things that make it ok and what are the things that make it difficult to have epilepsy. Then, we can help young people just like you in the future.

What will happen to my answers?

You will not be writing your name anywhere on the questionnaire so no one will know what you have answered. Your answers will be kept locked up safely so that no one else can see them. We will be writing a long essay about what you tell us but we will not mention your name in the essay. There are no right or wrong things to say, we are just really interested in finding out about what it is like to have epilepsy.

Can one of my parents stay with me while I fill in my answers?

Yes, of course, but if you want to you can also fill in your answers by yourself.

What should I do if I do not want to take part?

That is fine. We will respect your wishes. We won't mind at all.

If you have any questions you want to ask us before you fill in your answers, you can ask your parents if it would be ok for you to contact us. We would be very happy to answer any questions you have.

talkingaboutepilepsy@gmail.com

Parent Information Sheet

Research Study: Talking about Epilepsy

What is this study about?

We are doing this study to find out more about you and your child's experiences of living with epilepsy. We are interested in learning about you and your child's experiences of talking/not talking about epilepsy and the impact of your discussions on your opinions of epilepsy as a condition. We are also interested in hearing about you and your child's experiences of telling/not telling, or talking/not talking, to others (e.g. friends, family members, teachers, etc.) about your child's epilepsy.

Who is conducting this study?

Led by Dr. Veronica Lambert, a team of researchers at the School of Nursing and Human Sciences in Dublin City University (DCU) and Temple Street Children's University Hospital (TSCUH) are conducting two studies in the area of communicating about epilepsy both within and external to the family. Two PhD researchers are currently working on these projects. Ailbhe is focusing on parents' and children's experiences of telling/not telling others about epilepsy, and Stephanie is focusing on parents' and children's experiences of talking about epilepsy within the family. These studies are Medical Research Charities Group (MRCG)/Health Research Board (HRB) funded and were developed in collaboration with the Neurology Department of TSCUH and Epilepsy Ireland - The Irish Epilepsy Association. The studies have received ethical approval from the research ethics committees in TSCUH, DCU and other regional paediatric units.

If I give consent to take part what will we be asked to do?

- The team of researchers has created one questionnaire designed to address the focus of both Ailbhe's and Stephanie's studies. We would like you to complete this questionnaire, either online or in paper form, about being the parent or guardian of a child living with epilepsy.
- Your child/children will also receive an information letter about completing a questionnaire about his/her epilepsy. Please be aware that you are under no obligation to share this information with your child, however doing so implies that you consent for your child to participate. The child information letter will be a simple, easier to read version. If you wish for your child to participate, we would encourage you to discuss the information letter with your child/children.
- If you complete the questionnaire in hard copy form, we would ask you to kindly return the questionnaire using the enclosed stamped addressed envelope.

How long will the process take?

- The questionnaire should take no longer than 1 hour to complete.

What if we do not decide to take part?

- We understand that not all families will have the time to take part in our study, and some families may not be interested. If you choose not to take part in the study, this will in *no way* affect your child's treatment in any of the affiliated hospitals or your participation in any activities/events organised by Epilepsy Ireland in the future

What will be done with the information collected by us?

- All the information you and your family provides will be de-identifiable (i.e. no one will be able to tell what you specifically answered).
- While completing the questionnaire, you may decide to stop participating and withdraw from the study at any time. However, as we will not be able to identify your data, once you have submitted the questionnaires (by post or online) we will not be able to withdraw you from the study.
- Only the research team and possibly the examiners of our theses will have access to the data and these will be treated in the strictest of confidence at all times.
- All information will be stored in locked filing cabinets and/or on password-protected computers in DCU.
- The information we collect from all the families who complete this questionnaire will be used to write a report on the findings of this research.
- The MRCG/Epilepsy Ireland and HRB who are funding the project will receive annual reports and the findings from the study may be published in journals. Additionally, we will write our theses using information we have gathered from families involved in this research.

How will this study be of benefit to me and my children?

While there may be no immediate benefits to you, and your child/children from taking part in the study, the researchers hope that studies such as these can be used to identify the needs of children living with epilepsy and thus inform and develop new services for families.

Are there any risks or downsides to taking part?

There should be no risks involved in taking part, however if you feel it might help to talk to somebody about any of the issues that came up, we can put you in touch with someone (e.g. your local Community Resource Officer in Epilepsy Ireland) who can advise you on next steps.

Is there anything else I need to know?

If you would like to talk informally with us about any questions or queries you may have about this research, please contact us by email at *talkingaboutepilepsy@gmail.com* or by phone –**01-7007997 (Ailbhe)** or **01-7006867 (Stephanie)***.*

Thank you for taking an interest in this research and completing this questionnaire!

If participants have concerns about this study and wish to contact an independent person, please contact:

The Secretary,
Dublin City University Research Ethics Committee,
Care of Research and Innovations Support,
Dublin City University,
Dublin 9.
Tel: 01-7008000

Appendix L3: Child/Young-Person Consent Form (Phase Two)

IF YOU WANT TO TAKE PART IN THIS PROJECT PLEASE FILL IN THE ANSWERS BELOW, OTHERWISE THANK YOU FOR YOUR TIME.

Please tick yes/no:

- I am aged 8 – 18 years and have epilepsy. ☐ Yes ☐ No
- I have read the information about the project. ☐ Yes ☐ No
- I agree to take part in the project. ☐ Yes ☐ No
- I am aware that I do not have to take part. ☐ Yes ☐ No
- I am aware that I can stop taking part at any time as long as I stop before sending back the questionnaire to Ailbhe and Stephanie. ☐ Yes ☐ No
- I am aware that Ailbhe and Stephanie may talk about the findings of the project or write about them, but nobody will know what I have answered. ☐ Yes ☐ No

In order to help us to link your and your parent's answers (if they are taking part), please list the following letters/numbers:

____ ___ ___ ___ ___ ___

*For example, if your name was '**Su**san Smi**th**' and you were **13** years old, you would enter;*

S U 1 3 T H

Appendix L4: Parent Consent Form (Phase Two)

IF YOU ARE INTERESTED IN PARTICIPATING IN THIS STUDY PLEASE PROVIDE YOUR CONSENT BELOW, OTHERWISE THANK YOU FOR YOUR TIME AND INTEREST.

Please tick yes/no:

- I am the parent/guardian of a child living with epilepsy aged 8 – 18 years. ☐ Yes ☐ No
- I have read the information in relation to the study. ☐ Yes ☐ No
- I agree to participate in the study. ☐ Yes ☐ No
- I am aware that my participation is voluntary. ☐ Yes ☐ No
- I am aware that I may withdraw before I post back the questionnaire or before I hit the submit button at the end of the questionnaire (online version). ☐ Yes ☐ No
- I am aware that the findings of the study may be reported at a conference or published. ☐ Yes ☐ No

In order to help us to link your and your child's answers (if he/she chooses to participate), please provide the following code:

____ ___ ___ ___ ___ ___

*E.g. – **Su**san Smi**th**, **13** years:*

S U 1 3 T H

Child/Young Person Questionnaire

Demographic Information (Section A)

In this section we would like to ask you a few questions about you and your epilepsy.

A1. What is your age?
____ years

A2. What is your gender?
☐ Female ☐ Male

A3. Please state your ethnicity.
☐ Caucasian/White ☐ Black or African American
☐ Hispanic or Latino ☐ Asian / Pacific Islander
☐ Arab ☐ Multiracial
☐ Would rather not say ☐ Other

If other, please state: _____

A4. What type of seizures do you have or have you had in the past?
(Please tick all relevant to you)
☐ Tonic-clonic seizures
(You fall down; your body stiffens and shakes)
☐ Absence seizures
(You seem to daydream or "switch off" for a few seconds, you might not be aware of where you are or what has happened)
☐ Simple Partial
(You have partial seizures in which you are fully awake, alert and able to communicate during the seizure)
☐ Complex Partial
(You have partial seizures in which you might not be aware of where you are or what has happened and you might stare blankly)
☐ Myoclonic seizures
(Your muscles in your arms, legs or face briefly jerk or twitch, you will usually be awake and able to think clearly)
☐ Atonic seizures
(Drop attacks; you may drop to the ground suddenly without any warning. In some people, only their head suddenly drops)
☐ Tonic seizures
(Your arms or legs make sudden stiffening movements, you are usually aware that this is happening)
☐ Clonic seizures
(Your arms and legs jerk/shake over and over again)
☐ Other, please describe:

A5. Have you ever had seizures when you were with anyone other than your parents or brother/sister?
☐ Yes ☐ No
If you answered yes, please list who has seen you have a seizure:

A6. At what age did you have your first seizure?

Age: _____ (years)

A7. How frequent are your seizures currently?

☐ Daily *(once a day or more)*
☐ Frequently *(several times a week)*
☐ Weekly *(about once a week)*
☐ Monthly *(about once a month)*
☐ Occasionally *(less than monthly)*
☐ Yearly *(about once a year)*
☐ Other, please describe:

A8. When was your last seizure?

A9. Are you currently receiving treatment or taking medication for your epilepsy?

☐ Yes ⇨ Please provide details of what medication(s) you currently use and how often you take them in the box below.

Please provide details of any medication(s) you used to use and how often you used to take them in the box below.

☐ No ⇨ When did you stop using/receiving treatment/taking medication?

(M)	(M)	(Y)	(Y)	(Y)	(Y)

Please provide details of any medication(s) you used to use and how often you used to take them in the box below.

A10. Have you experienced any side effects as a result of treatment or medication?

☐ Yes ☐ No

If you answered yes, please list the side effects experienced:

A11. Have you missed any days of school as a result of your epilepsy?
☐ Yes ☐ No

If you answered yes, please state the number of days within the past year

____ days (roughly)

A12. What county are you currently living in?

A13. Please tell us what you call your epilepsy in your own words.

A.14 At hospital appointments, do you find talking to doctors and nurses (etc.) ok?
☐ Yes ☐ No

Please tell us more:

A15. Where did you complete this questionnaire?
☐ At home ☐ In a healthcare facility
☐ Other, please describe:

A16. Was your parent present as you completed this questionnaire?
☐ Yes ☐ No

A17. Where did you hear about this project?
☐ Epilepsy Ireland ☐ Temple Street Children's University Hospital
☐ Other, please describe:

End of Section A

Section B

Do I tell and talk to others about my epilepsy?
Please read each statement carefully. Indicate how you feel by ticking the box that you most agree with for each statement.

B1. When you can, do you keep your epilepsy a secret from others?
☐ Often ❑ Sometimes ❑ Rarely ❑ Never

B2. How frequently do you talk to people outside your family about your epilepsy?
☐ Often ❑ Sometimes ❑ Rarely ❑ Never

B3. Do any of your friends know that you have epilepsy?
☐ All ❑ Some ❑ Few ❑ None

B4. When people find out you have epilepsy, it is usually because:
☐ You tell them
❑ You have a seizure and then you explain it
❑ You have a seizure and they see it
❑ Someone else tells them about it

B5. How difficult has it been for you to talk to others about what you are going through?
☐ Not at all ❑ A little ❑ Somewhat ❑ Very

B6. How much have you wanted someone to talk to about your experience with epilepsy?
☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B7. To what degree have you *wanted to keep* your epilepsy a secret?
☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B8. To what degree have you *actually kept* your epilepsy a secret?
☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B9. How much have you written about your epilepsy (such as in a diary, journal, letters or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?
☐ Not at all ❑ A little ❑ Somewhat ❑ A lot

B10. If you have written about your epilepsy, where have you written about it?

Diary/Journal	☐ Yes	☐ No
Letters	☐ Yes	☐ No
Facebook	☐ Yes	☐ No
Twitter	☐ Yes	☐ No
Epilepsy Support Groups	☐ Yes	☐ No
Tumblr	☐ Yes	☐ No
Blogs	☐ Yes	☐ No
Any other sources	☐ Yes	☐ No

Please write down where else you have written about your epilepsy below:

Who do I tell and talk to about my epilepsy?

B11. Using the scale below, please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your diagnosis: (please mark "0" next to any categories that do not apply to you).

0 Not Applicable | 1 Not at all | 2 A little | 3 Somewhat | 4 Very Much

_____	Boyfriend or Girlfriend	_____	Close male friend(s)
_____	Close female friend(s)	_____	Male friend(s)
_____	Female friend(s)	_____	Neighbour(s)
_____	Classmates	_____	Therapist/Counsellor
_____	Other Adults with Epilepsy	_____	Doctors
_____	Nurses	_____	Mother
_____	Father	_____	Older sisters(s)
_____	Older brother(s)	_____	Younger sisters(s)
_____	Younger brother(s)	_____	Co-workers
_____	Grandparents	_____	Aunts/Uncles
_____	Cousins	_____	Employers
_____	Your friends' parents	_____	Your teacher(s)
_____	Your principal	_____	Your sports club coaches
_____	Your sports team members	_____	Other Young People with Epilepsy
_____	Your child-minder/nanny/au pair	_____	Young People with Illnesses
_____	Young People with something that makes them different		

Other, please list: _____

B12. As far as you are aware, which of the following adults know that you have epilepsy? (Please tick a box for each person listed).

The principal	☐ Yes	☐ No	☐ Not applicable
Your head of year teacher	☐ Yes	☐ No	☐ Not applicable
Your class teachers overall	☐ Yes	☐ No	☐ Not applicable
Your PE teacher	☐ Yes	☐ No	☐ Not applicable
Your sports coaches	☐ Yes	☐ No	☐ Not applicable
Your friends' parents	☐ Yes	☐ No	☐ Not applicable
Your babysitter	☐ Yes	☐ No	☐ Not applicable
Your child-minder/nanny/au pair	☐ Yes	☐ No	☐ Not applicable
Your grandparents	☐ Yes	☐ No	☐ Not applicable
Your aunts/uncles	☐ Yes	☐ No	☐ Not applicable
Your parents' friends	☐ Yes	☐ No	☐ Not applicable
Any other adults	☐ Yes	☐ No	☐ Not applicable

Please write down who this person is in relation to you or what this person does (**not** their name):

B13. As far as you are aware, which of the following children at school or college know that you have epilepsy?

None of the other children know	☐ Yes	☐ No
My best friend only	☐ Yes	☐ No
My few best friends only	☐ Yes	☐ No
Most of the other children in my class only	☐ Yes	☐ No
Most of the other children in the school	☐ Yes	☐ No
Any other children	☐ Yes	☐ No

Please write down who these children are in relation to you (**not** their name):

When do I tell and talk to others about my epilepsy?

In this section, we want to find out in what types of situations you usually tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy.

I usually tell and talk to others about my epilepsy when…

B14. I have had a seizure that others have seen (e.g. in school etc.)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B15. I have had a seizure that others have not seen (e.g. at home etc.)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B16. I feel like I might have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B17. Others see me taking my medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B18. Others ask me questions
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B19. My medication is causing me difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B20. I have a hospital appointment coming up or I have recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B21. I cannot take part in an activity because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B22. I miss school because I have had a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B23. I need support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B24. Epilepsy comes up in conversation
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

I usually tell and talk to others about my epilepsy when…

B25. I am starting a new activity or sport
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B26. I am meeting new people
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B27. My friends are telling me their secrets
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B28. Other, please describe:

What do I tell others when I am talking to them about my epilepsy?

In this section, we are interested in finding out what kind of things you usually tell and talk to others (including friends, classmates, team members and those outside the family) about in relation to your epilepsy.

When I talk to others about my epilepsy, I talk to them about…

B29. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B30. The type of epilepsy I have
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B31. What happens when I have a seizure (e.g. what I look like)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B32. How seizures affect me
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B33. What they should do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B34. My medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B35. The medication side-effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B36. My hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B37. Things I cannot take part in because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B38. Whether my seizures are controlled or not
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B39. Whether I will grow out of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B40. How I feel about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my epilepsy

B41. Other, please describe:

Why do I choose to talk to or not talk to others about my epilepsy?

In this section, we are interested in finding out what kind of things make you decide to tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy, as well as what kind of things make you decide not to tell and talk to others about your epilepsy.

I tell others about my epilepsy because…

B42. I want them to know I might have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B43. I want them to know what to do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B44. I want others to learn about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B45. Talking to others about my epilepsy makes me feel better
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

I tell others about my epilepsy because…

B46. Talking to others about my epilepsy helps me to learn more about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B47. It makes me feel more comfortable when others know about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my epilepsy

B48. Other, please describe:

I don't tell others about my epilepsy because…

B49. It makes me feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B50. I am worried others will treat me differently
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B51. I am scared of how people will react
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B52. I think people might tease me
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B53. I don't want people to spread it around
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B54. Others do not think good things about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B55. It makes me sad
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B56. My parents think that epilepsy is something we should keep private
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B57. Nobody else I know has epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

I don't tell others about my epilepsy because…

B58. Others cannot see that I have epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B59. Others do not need to know I have epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B60. My epilepsy is private/secret
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B61. I don't want to seem like I am looking for attention
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my epilepsy

B62. Other, please describe:

What helps or hinders me when talking to others about my epilepsy?

In this section, we are interested in finding out what you find helpful or challenging when telling and talking to others (including friends, classmates, team members and those outside the family) about your epilepsy.

Do any of the following things help or make it challenging for me to tell and talk to other people about my epilepsy?

B63. How often I have seizures
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B64. How I feel about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B65. How much I know about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B66. Knowing others with epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B67. How others have reacted when I have told them about my epilepsy in the past
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B68. How much others know about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

Do any of the following things help or make it challenging for me to tell and talk to other people about my epilepsy?

B69. If other people have something that makes them different
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B70. Whether other people can see that I have epilepsy (e.g. if I have had seizures in front of them or not)
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B71. How long I have had epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B72. How well I can explain epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B73. How epilepsy makes me feel
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B74. How other people might treat me
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B75. What other people think about epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B76. Whether other people understand epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B77. When epilepsy is on TV or on the radio
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B78. When I hear that famous people have epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

B79. Other, please describe:

What happens when I talk to others about my epilepsy?

In this section, we are interested in finding out how it makes you feel to tell and talk to others (including friends, classmates, team members and those outside the family) about your epilepsy and how others react when you tell them about your epilepsy.

Before telling others about my epilepsy I feel…

B80. Worried/Nervous
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B81. Embarrassed/Ashamed
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B82. Different
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B83. Afraid
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B84. Uneasy
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B85. Confident
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B86. Hopeful
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B87. Brave
☐ Yes ☐ No ☐ Does not apply, I never tell others about my epilepsy

B88. Others, please list:

In the past, when I have told others about my epilepsy they have…

B89. Been kind about it
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B90. Been mean about it
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B91. Asked me questions
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

In the past, when I have told others about my epilepsy they have…

B92. Made me feel better about it
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B93. Found it difficult to understand
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B94. Laughed at or teased me about it
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B95. Treated me differently
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B96. Made me feel left out
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B97. Been scared of me
☐ Yes ☐ No ☐ Does not apply, I have never told others about my epilepsy

B98. Others, please list:

After telling others about my epilepsy when they react well I feel…

B99. Happy
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B100. Better
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B101. Relieved
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my epilepsy

B102. Others, please list:

After telling others about my epilepsy when they react poorly I feel…

B103. Embarrassed/Ashamed
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

After telling others about my epilepsy when they react poorly I feel…

B104. Different
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B105. Silly
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B106. Sad
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B107. Angry/ Mad
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B108. Worried
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my epilepsy

B109. Others, please list:

End of Section B

Section C

When do I talk to my parents about my epilepsy?

In this section, we are interested in what types of situations you talk to your Mum or Dad about your epilepsy.

I usually talk to my Mum or Dad about my epilepsy when…

C1. I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C2. I take my medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C3. My medication is causing me difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

I usually talk to my Mum or Dad about my epilepsy when…

C4. I have a question about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C5. I have a hospital appointment coming up or I have recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C6. I cannot take part in an activity because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C7. I am worried/ upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C8. I need support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C9. Other, please describe:

When I talk to my Mum or Dad about my epilepsy, what do we talk about?

When I talk to my Mum or Dad about my epilepsy, we talk about…

C10. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C11. How I feel about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C12. What happens when I have a seizure (e.g. what I look like)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C13. My medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C14. Medication side effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

When I talk to my Mum or Dad about my epilepsy, we talk about…

C15. My hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C16. Things I cannot take part in because of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C17. Whether my seizures are controlled or not
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C18. Whether I will grow out of my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C19. Other, please describe:

Why do I choose to talk to my Mum or Dad about my epilepsy?

In this section we are interested in what kinds of things make you decide to talk to your Mum or Dad about your epilepsy, as well as what kinds of things make you decide to not talk to your Mum or Dad about your epilepsy.

I talk to my Mum or Dad about my epilepsy because…

C20. I don't want to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C21. I want to know what I should do if I have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C22. It helps me to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C23. I want to know a lot about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C24. I don't want to keep secrets about my epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my Mum or Dad about my epilepsy

C25. Others, please list

I don't talk to my Mum or Dad about my epilepsy because…

C26. I don't want to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C27. I don't want to worry my Mum or Dad
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C28. I don't want my Mum or Dad to think I am looking for attention
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C29. If I talk to my Mum or Dad they might not let me go to things
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C30. My Mum or Dad will make a big deal about it
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my Mum or Dad about my epilepsy

C31. Other, please describe:

What helps or hinders me when talking to my Mum or Dad about my epilepsy?

In this section we are interested in what you find helpful or challenging when talking to your Mum or Dad about your epilepsy.

Do any of the following things help or make it challenging for me to talk to my Mum or Dad about my epilepsy?

C32. How much I usually talk to my Mum and Dad about things
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C33. The amount of time that I have had epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C34. How much I know about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C35. How often I have seizures
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C36. When epilepsy is on the T.V. or radio
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

Do any of the following things help or make it challenging for me to talk to my Mum or Dad about my epilepsy?

C37. How I feel about my epilepsy
☐ This helps me ☐ This makes it difficult ☐ This makes no difference

C38. Others, please list:

What happens when I talk to my Mum or Dad about my epilepsy?

In this section, we are interested in finding out how talking to your Mum or Dad about your epilepsy makes you feel.

Talking about my epilepsy with my Mum or Dad makes me feel…

C39. Happy
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C40. Sad
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C41. Worried
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C42. Brave
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C43. Embarrassed
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C44. Different
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C45. Special
☐ Yes ☐ No ☐ Does not apply, I never talk to my Mum or Dad about my epilepsy

C46. Other, please list:

End of Section C

Section D

In this section, we would like to ask you some questions about how you feel about your epilepsy. Each time please tell us how often you have these feelings.

D1. How often do you feel different from other kids because you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D2. How often do you feel people may not like you if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D3. How often do you feel other children are uncomfortable with you because of your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D4. How often do you feel people may not want to be friends with you if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D5. How often do you feel people would not want to go out with you or ask you to parties if they know you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D6. How often do you feel embarrassed about your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D7. How often do you keep your epilepsy a secret from other kids?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D8. How often do you try to avoid talking to other people about your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D9. How good or bad do you feel it is that you have epilepsy?

☐ Very Good
☐ A Little Good
☐ Not Sure
☐ A Little Bad
☐ Very Bad

D10. How fair is it that you have epilepsy?

☐ Very Fair
☐ A Little Fair
☐ Not Sure
☐ A Little Unfair
☐ Very Unfair

D11. How happy or sad is it for you to have epilepsy?

☐ Very Sad
☐ A Little Sad
☐ Not Sure
☐ A Little Happy
☐ Very Happy

D12. How bad or good do you feel it is to have epilepsy?

☐ Very Good
☐ A Little Good
☐ Not Sure
☐ A Little Bad
☐ Very Bad

D13. How often do you feel that your epilepsy is your fault?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D14. How often do you feel that your epilepsy keeps you from doing things you like to do?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D15. How often do you feel that you will always be sick?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D16. How often do you feel that your epilepsy keeps you from starting new things?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D17. How often do you feel different from others because of your epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D18. How often do you feel bad because you have epilepsy?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

D19. How often do you feel sad about being sick?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D20. How often do you feel happy even though you have epilepsy?

☐ Never
☐ Not Often
☐ Sometimes
☐ Often
☐ Very Often

D21. How often do you feel just as good as other kids your age even though you have epilepsy?

☐ Very Often
☐ Often
☐ Sometimes
☐ Not Often
☐ Never

End of Section D

What Am I Like and People in My Life? (Section E)

In this section, we are interested in what each of you is like, what kind of a person you are like and the people in your life. This is a survey, not a test. There are no right or wrong answers. Since kids are very different from one another, each of you will be putting down something different.

First, let me explain how these questions work. There is a sample question at the top, marked (a). This question talks about two kinds of kids, and we want to know which kids are most like you.

1) So, what I want you to decide first is whether you are more like the kids on the left side who would rather play outdoors, or whether you are more like the kids on the right side who would rather watch T.V. Don't mark anything yet, but first decide which kinds of kids are most like you, and go to that side of the sentence.

2) Now the second thing I want you to think about, now that you have decided which kinds of kids are most like you, is to decide whether that is only sort of true for you, or really true for you. If it's only sort of true, then put an X in the box under Sort of True for me; if it's really true for you, then put an X in that box, under Really True for me.

3) For each sentence, you only check one box. Sometimes it will be on one side of the page, another time it will be on the other side of the page, but you can only check one box for each sentence. **You don't check both sides, just the one side most like you.**

4) Ok, that one was just for practice. **Now we have some more sentences. For each one, just check one box - the one that goes with what is true for you, what you are most like.**

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
Sample Sentence							
a.	☐	☐	**Some kids would rather play outdoors in their spare time**	**but**	**Other kids would rather watch T.V.**	☐	☐

Appendix L5: Child/Young-Person Questionnaire (Phase Two) (continued)

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E1	☐	☐	**Some kids feel that they are very good at their school work**	**but**	**Other kids worry about whether they can do the school work assigned to them**	☐	☐
E2	☐	☐	**Some kids find it hard to make friends**	**but**	**Other kids find it pretty easy to make friends**	☐	☐
E3	☐	☐	**Some kids do very well at all kinds of sports**	**but**	**Other kids don't feel that they are very good when it comes to sports**	☐	☐
E4	☐	☐	**Some kids are happy with the way they look**	**but**	**Other kids are not happy with the way they look**	☐	☐
E5	☐	☐	**Some kids often do not like the way they behave**	**but**	**Other kids usually like the way they behave**	☐	☐
E6	☐	☐	**Some kids are often unhappy with themselves**	**but**	**Other kids are pretty pleased with themselves**	☐	☐
E7	☐	☐	**Some kids feel like they are just as smart as other kids their age**	**but**	**Other kids aren't so sure and wonder if they are as smart**	☐	☐
E8	☐	☐	**Some kids know how to make classmates like them**	**but**	**Other kids don't know how to make classmates like them**	☐	☐
E9	☐	☐	**Some kids wish they could be a lot better at sports**	**but**	**Other kids feel they are good enough at sports**	☐	☐
E10	☐	☐	**Some kids are happy with their height and weight**	**but**	**Other kids wish their height or weight were different**	☐	☐
E11	☐	☐	**Some kids usually do the right thing**	**but**	**Other kids often don't do the right thing**	☐	☐
E12	☐	☐	**Some kids don't like the way they are leading their life**	**but**	**Other kids do like the way they are leading their life**	☐	☐
E13	☐	☐	**Some kids are pretty slow in finishing their school work**	**but**	**Other kids can do their school work quickly**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E14	☐	☐	**Some kids don't have the social skills to make friends**	**but**	**Other kids do have the social skills to make friends**	☐	☐
E15	☐	☐	**Some kids think they could do well at just about any new sports activity they haven't tried before**	**but**	**Other kids are afraid they might not do well at sports they haven't ever tried**	☐	☐
E16	☐	☐	**Some kids wish their body was different**	**but**	**Other kids like their body the way it is**	☐	☐
E17	☐	☐	**Some kids usually act the way they know they are supposed to**	**but**	**Other kids often don't act the way they are supposed to**	☐	☐
E18	☐	☐	**Some kids are happy with themselves as a person**	**but**	**Other kids are often not happy with themselves**	☐	☐
E19	☐	☐	**Some kids often forget what they learn**	**but**	**Other kids can remember things easily**	☐	☐
E20	☐	☐	**Some kids understand how to get peers to accept them**	**but**	**Other kids don't understand how to get peers to accept them**	☐	☐
E21	☐	☐	**Some kids feel that they are better than others their age at sports**	**but**	**Other kids don't feel they can play as well**	☐	☐
E22	☐	☐	**Some kids wish their physical appearance (how they look) was different**	**but**	**Other kids like their physical appearance the way it is**	☐	☐
E23	☐	☐	**Some kids usually get in trouble because of things they do**	**but**	**Other kids usually don't do things that get them in trouble**	☐	☐
E24	☐	☐	**Some kids like the kind of person they are**	**but**	**Other kids often wish they were someone else**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E25	☐	☐	**Some kids do very well at their classwork**	**but**	**Other kids don't do very well at their classwork**	☐	☐
E26	☐	☐	**Some kids wish they knew how to make more friends**	**but**	**Other kids know how to make as many friends as they want**	☐	☐
E27	☐	☐	**In games and sports, some kids usually watch instead of play**	**but**	**Other kids usually play rather than just watch**	☐	☐
E28	☐	☐	**Some kids wish something about their face or hair looked different**	**but**	**Other kids like their face and hair the way they are**	☐	☐
E29	☐	☐	**Some kids do things they know they shouldn't do**	**but**	**Other kids hardly ever do things they know they shouldn't do**	☐	☐
E30	☐	☐	**Some kids are very happy being the way they are**	**but**	**Other kids wish they were different**	☐	☐
E31	☐	☐	**Some kids have trouble figuring out the answers in school**	**but**	**Other kids almost always can figure out the answers**	☐	☐
E32	☐	☐	**Some kids know how to become popular**	**but**	**Other kids do not know how to become popular**	☐	☐
E33	☐	☐	**Some kids don't do well at new outdoor games**	**but**	**Other kids are good at new games right away**	☐	☐
E34	☐	☐	**Some kids think that they are good looking**	**but**	**Other kids think that they are not very good looking**	☐	☐
E35	☐	☐	**Some kids behave themselves very well**	**but**	**Other kids often find it hard to behave themselves**	☐	☐
E36	☐	☐	**Some kids are not very happy with the way they do a lot of things**	**but**	**Other kids think the way they do things is fine**	☐	☐

Appendix L5: Child/Young-Person Questionnaire (Phase Two) (continued)

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E37	☐	☐	**Some kids with epilepsy say kids won't play with them.**	**but**	**Other kids with epilepsy say other kids always play with them.**	☐	☐
E38	☐	☐	**Some kids with epilepsy think they are not as good at things as other kids are.**	**but**	**Other kids with epilepsy think they are just as good at things as other kids are.**	☐	☐
E39	☐	☐	**Some kids with epilepsy don't have many friends.**	**but**	**Other kids with epilepsy have lots of friends.**	☐	☐
E40	☐	☐	**Some kids with epilepsy feel that other kids treat them differently.**	**but**	**Other kids with epilepsy feel that they are treated the same as everyone.**	☐	☐
E41	☐	☐	**Some kids with epilepsy feel like they are being picked on.**	**but**	**Other kids with epilepsy don't feel they get picked on.**	☐	☐
E42	☐	☐	**Some kids always have to think about their epilepsy before doing things.**	**but**	**Other kids don't think about their epilepsy before doing things.**	☐	☐
E43	☐	☐	**Some kids with epilepsy think their parents are worried that they will hurt themselves.**	**but**	**Other kids with epilepsy don't think their parents are worried about them.**	☐	☐
E44	☐	☐	**Some kids with epilepsy may not be able to go away to camp or similar places.**	**but**	**Other kids with epilepsy can go away to camp or similar places if they want to.**	☐	☐
E45	☐	☐	**Some kids worry about what might happen to them if they forget to take their medicine.**	**but**	**Other kids are not worried about what might happen if they forget to take their medicine.**	☐	☐
E46	☐	☐	**Some kids worry about getting hurt during a seizure.**	**but**	**Other kids are not worried about getting hurt during a seizure.**	☐	☐

Appendix L5: Child/Young-Person Questionnaire (Phase Two) (continued)

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E47	☐	☐	**Some kids with epilepsy get upset easily.**	**but**	**Other kids with epilepsy do not get upset easily.**	☐	☐
E48	☐	☐	**Some kids with epilepsy have trouble paying attention at school.**	**but**	**Other kids with epilepsy can concentrate well at school.**	☐	☐
E49	☐	☐	**Some kids with epilepsy get angry easily.**	**but**	**Other kids with epilepsy do not get angry easily.**	☐	☐
E50	☐	☐	**Some kids with epilepsy have trouble remembering things they learned at school.**	**but**	**Other kids with epilepsy can easily remember things they learned at school.**	☐	☐
E51	☐	☐	**Some kids feel they will have to take seizure medicine for the rest of their life.**	**but**	**Other kids feel they could soon stop taking medicine for their seizures.**	☐	☐
E52	☐	☐	**Some kids feel OK telling people about their epilepsy.**	**but**	**Other kids are nervous telling people about their epilepsy.**	☐	☐
E53	☐	☐	**Some kids are afraid that their friends will find out they have epilepsy.**	**but**	**Other kids don't mind if their friends find out they have epilepsy.**	☐	☐
E54	☐	☐	**Some kids with epilepsy feel safe away from home.**	**but**	**Other kids with epilepsy do not feel safe away from home.**	☐	☐
E55	☐	☐	**Some kids feel embarrassed to have epilepsy.**	**but**	**Other kids are not embarrassed to have epilepsy.**	☐	☐
E56	☐	☐	**Some kids with epilepsy feel their friends are a bit afraid of them.**	**but**	**Other kids with epilepsy feel their friends are not afraid of them.**	☐	☐
E57	☐	☐	**Some kids with epilepsy are treated the same as their brothers and sisters.**	**but**	**Other kids with epilepsy are treated differently than their brothers and sisters.**	☐	☐

Appendix L5: Child/Young-Person Questionnaire (Phase Two) (continued)

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E58	☐	☐	**Some kids live a normal life even though they have seizures.**	**but**	**Other kids can't live a normal life because of their seizures.**	☐	☐
E59	☐	☐	**Some kids with epilepsy feel their teachers treat them the same as other kids at school.**	**but**	**Other kids with epilepsy feel that their teachers treat them differently from other kids at school.**	☐	☐
E60	☐	☐	**Some kids do not let their epilepsy slow them down.**	**but**	**Other kids get slowed down by their epilepsy.**	☐	☐
E61	☐	☐	**Some kids with epilepsy feel comfortable at school.**	**but**	**Other kids with epilepsy feel nervous at school.**	☐	☐
E62	☐	☐	**Some kids have parents who don't really understand them.**	**but**	**Other kids have parents who really do understand them.**	☐	☐
E63	☐	☐	**Some kids have classmates who like them the way they are**	**but**	**Other kids have classmates who wish they were different**	☐	☐
E64	☐	☐	**Some kids have a teacher who helps them if they are upset or have a problem**	**but**	**Other kids don't have a teacher who helps them if they are upset or have a problem**	☐	☐
E65	☐	☐	**Some kids have a close friend who they can tell problems to**	**but**	**Other kids don't have a close friend who they can tell problems to**	☐	☐
E66	☐	☐	**Some kids have parents who don't seem to want to hear about their children's problems**	**but**	**Other kids have parents who do want to listen to their children's problems**	☐	☐
E67	☐	☐	**Some kids have classmates they can become friendly with**	**but**	**Other kids don't have classmates that they can become friendly with**	☐	☐

Appendix L5: Child/Young-Person Questionnaire (Phase Two) (continued)

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E68	☐	☐	**Some kids don't have a teacher who helps them to do their very best**	**but**	**Other kids do have a teacher who helps them to do their very best**	☐	☐
E69	☐	☐	**Some kids have a close friend who really understands them**	**but**	**Other kids don't have a close friend who really understands them**	☐	☐
E70	☐	☐	**Some kids have parents who care about their feelings**	**but**	**Other kids have parents who don't seem to care very much about their feelings**	☐	☐
E71	☐	☐	**Some kids have classmates who sometimes make fun of them**	**but**	**Other kids don't have classmates who make fun of them**	☐	☐
E72	☐	☐	**Some kids do have a teacher who cares about them**	**but**	**Other kids don't have a teacher who cares about them**	☐	☐
E73	☐	☐	**Some kids have a close friend who they can talk to about things that bother them**	**but**	**Other kids don't have a close friend who they can talk to about things that bother them**	☐	☐
E74	☐	☐	**Some kids have parents who treat their child like a person who really matters**	**but**	**Other kids have parents who don't usually treat their child like a person who matters**	☐	☐
E75	☐	☐	**Some kids have classmates who pay attention to what they say**	**but**	**Other kids have classmates who usually don't pay attention to what they say**	☐	☐
E76	☐	☐	**Some kids don't have a teacher who is fair to them**	**but**	**Other kids do have a teacher who is fair to them**	☐	☐
E77	☐	☐	**Some kids don't have a close friend who they like to spend time with**	**but**	**Other kids do have a close friend who they like to spend time with**	☐	☐

	1 Really true for me	2 Sort of true for me				3 Sort of true for me	4 Really true for me
E78	☐	☐	**Some kids have parents who like them the way they are**	**but**	**Other kids have parents who wish their children were different**	☐	☐
E79	☐	☐	**Some kids don't get asked to play in games with classmates very often**	**but**	**Other kids often get asked to play in games by their classmates**	☐	☐
E80	☐	☐	**Some kids don't have a teacher who cares if they feel bad**	**but**	**Other kids do have a teacher who cares if they feel bad**	☐	☐
E81	☐	☐	**Some kids don't have a close friend who really listens to what they say**	**but**	**Other kids do have a close friend who really listens to what they say**	☐	☐
E82	☐	☐	**Some kids have parents who don't act like what their children do is important**	**but**	**Other kids have parents who do act like what their children do is important**	☐	☐
E83	☐	☐	**Some kids often spend their break being alone**	**but**	**Other kids spend break playing with their classmates**	☐	☐
E84	☐	☐	**Some kids have a teacher who treats them like a person**	**but**	**Other kids don't have a teacher who treats them like a person**	☐	☐
E85	☐	☐	**Some kids don't have a close friend who cares about their feelings**	**but**	**Other kids do have a close friend who cares about their feelings**	☐	☐

End of Section E

Section F

We are interested in how you and your parents communicate.

Please tick the box that describes your parents best for the next 23 statements:

F1. My parents often say things like "You'll know better when you grow up."

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F2. My parents often say things like "My ideas are right and you should not question them."

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F3. My parents often say things like "A child should not argue with adults."

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F4. My parents often say things like "There are some things that are just not to be talked about."

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F5. When anything really important is involved, my parents expect me to obey without question.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F6. In our home, my parents usually have the last word.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F7. My parents feel that it is important to be the boss.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F8. My parents sometimes become irritated with my views if they are different from theirs.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F9. If my parents don't approve of it, they don't want to know about it.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F10. When I am at home, I am expected to obey my parents' rules.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F11. My parents often ask my opinion when the family is talking about something.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F12. My parents encourage me to challenge their ideas and beliefs.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F13. I usually tell my parents what I am thinking about things.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F14. I can tell my parents almost anything.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F15. I talk to my parents about feelings and emotions.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F16. My parents and I often have long, relaxed conversations about nothing in particular.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F17. I really enjoy talking with my parents, even when we disagree.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F18. My parents often say something like "You should always look at both sides of an issue".

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F19. My parents like to hear my opinion, even when I don't agree with them.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F20. My parents encourage me to express my feelings.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F21. My parents tend to be very open about their emotions.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F22. We often talk as a family about things we have done during the day.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

F23. In our family, we often talk about our plans and hopes for the future.

☐ Strongly Agree ☐ Disagree
☐ Agree ☐ Strongly Disagree
☐ Neither Agree nor Disagree

End of Section F

Section G

We are interested in your visits with the doctors and nurses.

For each of the following 6 statements we would like for you to pick the response that best describes how you feel.

G1. The doctors and nurses explained my epilepsy to me

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G2. The doctors and nurses told me how the medicine worked

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G3. The doctors and nurses told me about possible problems or side effects with the medicine

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G4. The doctors and nurses told me things I can and cannot do because of seizures

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G5. I have had a chance to ask questions about my epilepsy

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

G6. The doctors and nurses talked to me about my fears and worries about my epilepsy

☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

We are interested in the areas where you want or need more information or more help with your seizures.

Please answer each of the next 12 questions with a yes or no
.

At this time…

G7. Would you like more information about your epilepsy?
☐ Yes ☐ No

G8. Would you like more information about your medication?
☐ Yes ☐ No

G9. Would you like more information about possible causes of your epilepsy?
☐ Yes ☐ No

G10. Would you like more information about how to handle future seizures?
☐ Yes ☐ No

G11. Would you like more information about any activities or things you can or cannot do because of your seizures?
☐ Yes ☐ No

G12. Would you like more information about keeping safe during a seizure?
☐ Yes ☐ No

G13. Would you like to talk to someone about your feelings about having epilepsy?
☐ Yes ☐ No

G14. Would you like to talk to someone about how to tell your friends about your epilepsy?
☐ Yes ☐ No

G15. Would you like to talk to someone about any concerns or fears you have about having epilepsy?
☐ Yes ☐ No

G16. Would you like to talk to someone about how your epilepsy might affect your future?
☐ Yes ☐ No

G17. Would you like to talk to other kids your age who also have epilepsy?
☐ Yes ☐ No

G18. Would you like to talk to someone about how to handle seizures at school?
☐ Yes ☐ No

End of Section G

END OF QUESTIONNAIRE


DCU
Epilepsy Ireland
Temple Street
CHILDREN'S UNIVERSITY HOSPITAL
HRB
Health Research Board

Parent Questionnaire

Talking about Epilepsy

Demographic Information (Section A)

In this section we would like to ask you a few questions about yourself and your child.

A1. What is your age?
☐ 25 or under ☐ 26 – 40 ☐ 41 – 55 ☐ 56 or older

A2. What is your gender?
☐ Female ☐ Male

A3. What is your child's age?
____ years

A4. What is your child's gender?
☐ Female ☐ Male

A5. Please specify your ethnicity.
☐ Caucasian/White ☐ Black or African American ☐ Hispanic or Latino
☐ Asian / Pacific Islander ☐ Arab ☐ Multiracial
☐ Would rather not say ☐ Other
If other, please specify: _____

A6. Are you the legal parent/guardian of the child who usually provides the most care to him/her?
☐ Yes ☐ No

A7. Which of the following best describes your relationship to the child?
☐ Biological mother / father ☐ Grandparent
☐ Adoptive mother / father ☐ Aunt / Uncle
☐ Step-mother / Step-father ☐ Other relative / In-law
☐ Partner of child's parent ☐ Unrelated guardian
☐ Foster mother /father

A8. What is the highest level of education you have completed?
☐ Less than Junior Certificate ☐ Honours Bachelor Degree
☐ Junior Certificate ☐ Higher Diploma
☐ Leaving Certificate ☐ Master's Degree
☐ Higher Certificate ☐ Doctoral Degree
☐ Ordinary Bachelor Degree

A9. What type of seizures does your child currently have, or have they had in the past? *(Please tick all relevant to your child)*
☐ Tonic-clonic seizures
(Your child loses consciousness, his/her body goes stiff, he/she falls to the floor, his/her limbs jerk)
☐ Absence seizures
(Your child appears to daydream or "switch off" for a few seconds; he/she will experience a lapse in awareness)
☐ Simple Partial
(Your child experiences partial seizures in which he/she is fully awake, alert and able to interact throughout the seizure)
☐ Complex Partial
(Your child experiences partial seizures in which he/she experiences a loss of awareness and may stare blankly)
☐ Myoclonic seizures
(Your child experiences extremely brief shock-like jerks/twitches of a muscle or group of muscles, your child will usually be awake and able to think clearly)
☐ Atonic seizures
(Drop attacks; your child experiences an abrupt loss of muscle tone and may drop to the ground. In some children, only their head suddenly drops)

What type of seizures does your child currently have, or have they had in the past?
(Please tick all relevant to your child)

☐ Tonic seizures
(Your child's arms or legs make sudden stiffening movements, consciousness is usually preserved)
☐ Clonic seizures
(Your child experiences rhythmic jerking movements of the arms and legs)
☐ Other/Unknown, please describe:

A10. Has your child ever had seizures in the company of anyone besides his/her parents or siblings?
☐ Yes ☐ No
If you answered yes, please specify:

A11. Has your child been diagnosed with a specific type of epilepsy?
☐ Yes ☐ No ☐ Unsure
If you answered yes, please specify the diagnosis received:

A12. At what age did your child experience his/her first seizure?
Age: _____ (years)

A13. How frequent are your child's seizures currently?
☐ Daily *(once a day or more)*
☐ Frequently *(several times a week)*
☐ Weekly *(about once a week)*
☐ Monthly *(about once a month)*
☐ Occasionally *(less than monthly)*
☐ Yearly *(about once a year)*
☐ Other, please specify:

A14. When was your child's last seizure?

A15. Is your child currently receiving treatment or taking medication for his/her epilepsy?
☐ Yes ⇨ Please provide details of what medication(s) your child uses and how often your child takes them in the box below.

Please provide details of any medication(s) your child used to use and how often your child took them in the box below.

☐ No ⇨ When did your child cease receiving treatment/taking medication?

(M) (M) (Y) (Y) (Y) (Y)

Please provide details of any medication(s) your child used to use and how often your child took them in the box below.

A16. Has your child experienced any side effects as a result of treatment or medication?

☐ Yes ☐ No

If you answered yes, please list the side effects experienced:

A17. Is there a known cause for your child's epilepsy?

☐ Yes ☐ No

If you answered yes, please specify:

A18. Is there a history of epilepsy in your family?

☐ Yes ☐ No ☐ Unsure

If you answered yes, please specify what family member (if known):

A19. Has your child missed any days of school as a result of his/her epilepsy?

☐ Yes ☐ No

If you answered yes, please specify the number of days within the past year:

____ days (approximately)

A20. What county are you and your child currently living in?

A21. In relation to your child's epilepsy care, how accessible have you found healthcare services to date?

☐ Very easy to access ☐ Somewhat difficult to access

☐ Somewhat easy to access ☐ Very difficult to access

☐ Okay to access

A22. What services does your child currently attend for his/her epilepsy care?

☐ A Neurology Department in a Hospital ☐ A Paediatric/General Clinic in a Hospital

☐ A General Practitioner (GP)

☐ Other, please specify:

A23. Has your child seen a neurologist about his/her epilepsy?
☐ Yes ☐ No

A24. When receiving your child's epilepsy diagnosis, was your experience satisfactory?
☐ Yes ☐ No
Please expand:

A25. At hospital appointments, do you find communicating with health care providers satisfactory?
☐ Yes ☐ No
Please expand:

A26. Please tell us what you call your child's epilepsy in your own words.

A27. Does your child have any other medical conditions?
☐ Yes ☐ No
If you answered yes, please specify:

A28. Where did you complete this questionnaire?
☐ At home ☐ In a healthcare facility
☐ Other, please specify:

A29. Was your child present as you completed this questionnaire?
☐ Yes ☐ No

A30. Where did you hear about this research?
☐ Epilepsy Ireland ☐ Temple Street Children's University Hospital
☐ Other, please specify:

End of Section A

Do I tell others and talk to others about my child's epilepsy? (Section B)

In this section, we are interested in how you communicate about your child's epilepsy with others.
Please read each statement carefully. Indicate how you feel about each statement.

B1. When you can, do you keep your child's epilepsy a secret from others?
☐ Often ☐ Sometimes ❑ Rarely ❑ Never

B2 How frequently do you talk to people about your child's epilepsy?
☐ Often ☐ Sometimes ❑ Rarely ❑ Never

B3. Do any of your friends know that your child has epilepsy?
☐ All ❑ Some ❑ Few ❑ None

B4. When people find out your child has epilepsy, it is usually because:
☐ You tell them
☐ Your child has a seizure and then you explain it
☐ Your child has a seizure and they see it
☐ Someone else tells them about it

B5. How difficult has it been for you to talk to others about what you and your child are going through?
☐ Not at all ☐ A little ☐ Somewhat ❑ Very

B6. How much have you wanted someone to talk to about your experience with your child's epilepsy?
☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B7. To what degree have you *wanted to keep* your child's epilepsy a secret?
☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B8. To what degree have you *actually kept* your child's epilepsy a secret?
☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B9. How much have you written about your child's epilepsy (such as in a diary, journal, letters; or online in support groups or on social media i.e. Facebook, Twitter, Tumblr, blogs etc.)?
☐ Not at all ☐ A little ☐ Somewhat ❑ A lot

B10. If you have written about your child's epilepsy, where have you written about it?

Diary/Journal	☐ Yes	☐ No
Seizure control journals	☐ Yes	☐ No
Letters	☐ Yes	☐ No
Facebook	☐ Yes	☐ No
Twitter	☐ Yes	☐ No
Epilepsy Support Groups	☐ Yes	☐ No
Tumblr	☐ Yes	☐ No
Blogs	☐ Yes	☐ No
Any other sources	☐ Yes	☐ No

Please specify where else you have written about your child's epilepsy below:

B11. Who do I tell and talk to about my child's epilepsy?

Using the scale below, please indicate the degree to which you have talked with each of the following individuals about your experience with epilepsy since your child's diagnosis: (please mark "0" next to any categories that do not apply to you).

0	1	2	3	4
Not Applicable	Not at all	A little	Somewhat	Very Much

_____	Partner/Spouse	_____	Close male friend(s)
_____	Close female friend(s)	_____	Male friend(s)
_____	Female friend(s)	_____	Neighbour(s)
_____	Other People with Epilepsy	_____	Doctors
_____	Nurses	_____	Parent(s)
_____	Sibling(s)	_____	Therapist/Counsellor
_____	Co-workers	_____	Your child with epilepsy
_____	Your other younger child(ren)	_____	Your other older child(ren)
_____	Your child's friends' parents	_____	Your child's teacher(s)
_____	Your child's principal	_____	Babysitters
_____	Nannies/Child-minders/Au pairs	_____	Your child's sports coaches
_____	Your employer	_____	Your in-laws
_____	Other Parents of Children with Epilepsy		
_____	Parents of Children with Other Chronic Illnesses or Disabilities		

Other, please specify: _____

When do I tell and talk to others about my child's epilepsy?

We want to find out in what types of situations and how often you usually tell and talk to others *(including friends, colleagues, your child's teacher and those outside the family)* about your child's epilepsy.

I usually talk to others about my child's epilepsy when…

B12. They have seen my child having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B13. I think my child might be at risk of having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B14. They see my child taking his/her medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

I usually talk to others about my child's epilepsy when…

B15. They ask me questions
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B16. My child has a hospital appointment coming up or has recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B17. My child's medication is causing difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B18. My child cannot partake in an activity due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B19. My child misses school because he/she has had a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B20. I need support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B21. I need information
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B22. Epilepsy comes up in conversation
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B23. My child is entering a new environment or starting a new activity
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B24. Others will be responsible for my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B25. There is a change in my child's behaviour due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B26. Others are speaking about their child's difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B27. Other, please specify;

We are interested in finding out what kind of things you usually tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about in relation to your child's epilepsy. **When I talk to others about my child's epilepsy, I talk to others about…**

B28. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B29. The type of epilepsy my child has
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B30. What happens/how my child appears when he/she is having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B31. How seizures impact on my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B32. What to do in the event of my child having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B33. My child's medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B34. Medication side-effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B35. My child's hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B36. Restrictions my child experiences due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B37. My child's seizure control (or lack thereof)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B38. Whether my child will grow out of his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B39. How I feel about my child having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

B40. How my child feels about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to others about my child's epilepsy

When I talk to others about my child's epilepsy, I talk to others about…

B41. Other, please specify:

Why do I choose to talk to or not talk to others about my child's epilepsy?
We are interested in finding out what informs your decision whether to tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy or not.

I tell others about my child's epilepsy because…

B42. I want them to be aware that my child may have a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B43. I want them to know what to do in the event of my child having a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B44. I want to ensure others do not overreact if my child has a seizure in front of them
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B45. I want to raise awareness about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B46. I want to make sure people are comfortable with my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B47. I want to explain the changes in my child's behaviour
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B48. Talking to others helps me to learn more about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B49. Talking to others offers me emotional support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B50. It makes me feel more comfortable when others know about my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never tell others about my child's epilepsy

B51. Other, please specify:

I don't tell others about my child's epilepsy because…

B52. I am afraid of how others will react
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B53. I am anxious that my child will be discriminated against or excluded
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B54. Other people are misinformed about epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B55. Other people have difficulty understanding epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B56. Epilepsy is rarely spoken about in public
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B57. It makes me upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B58. My child does not want others to know about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B59. My child's epilepsy is not visible (i.e. he/she does not have seizures in public or during the day)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B60. I do not feel that it is necessary for others to know about my child's epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B61. My child's epilepsy is a private matter
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B62. I do not want to seem attention-seeking
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always tell others about my child's epilepsy

B63. Other, please specify:

What helps or hinders me when talking to others about my child's epilepsy?
We are interested in finding out what you find helpful or challenging when telling and talking to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy.
Do any of the following encourage or discourage you to talk about your child's epilepsy with others?

B64. Epilepsy is a medical condition
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B65. My child's seizures are well controlled
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B66. My child's epilepsy is mild in comparison to others
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B67. My child's epilepsy is not visible to others
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B68. The level of information I have about my child's epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B69. The amount of time that has passed since my child's diagnosis
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B70. Portrayals of epilepsy in the media
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B71. My own attitudes towards epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B72. Experiences I have had with epilepsy prior to my child's diagnosis
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B73. The reactions from others when I've talked about my child's epilepsy in the past
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B74. Public perceptions of epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B75. My ability to explain epilepsy to others
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

Do any of the following encourage or discourage you to talk about your child's epilepsy with others?

B76. How I feel others will treat/perceive my child
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B77. How talking about my child's epilepsy to others makes me feel
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B78. Public understanding about epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B79. Whether my child wants others to know about his/her epilepsy
☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk about my child's epilepsy

B80. Other, please specify:

What happens when I talk to others about my child's epilepsy?

We are interested in finding out how it makes you feel to tell and talk to others (including friends, colleagues, your child's teacher and those outside the family) about your child's epilepsy and how others react when you tell them about your child's epilepsy.

Before telling others about my child's epilepsy I feel…

B81. Anxious
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B82. Optimistic
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B83. Uncomfortable
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B84. Pessimistic
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B85. Confident
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B86. Fearful
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B87. Unsure
☐ Yes ☐ No ☐ Does not apply to me, I never tell others about my child's epilepsy

B88. Other, please specify:

In the past, when I have told others about my child's epilepsy others have mostly…

B89. Reacted positively
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B90. Asked questions
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B91. Reassured me
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B92. Had difficulty understanding the condition
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B93. Reacted negatively
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B94. Treated my child differently
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B95. Excluded or discriminated against my child
☐ Yes ☐ No ☐ Does not apply, I have never told others about my child's epilepsy

B96. Other, please specify:

After telling others about my child's epilepsy when they react well I feel…

B97. Happy
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my child's epilepsy

B98. Reassured
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my child's epilepsy

B99. Relieved
☐ Yes ☐ No ☐ Does not apply, others have never reacted well
☐ Does not apply, I never tell others about my child's epilepsy

B100. Other, please specify:

After telling others about my child's epilepsy when they react poorly I feel…

B101. Frustrated
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my child's epilepsy

B102. Angered
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my child's epilepsy

B103. Upset
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my child's epilepsy

B104. Worried
☐ Yes ☐ No ☐ Does not apply, others have never reacted poorly
☐ Does not apply, I never tell others about my child's epilepsy

B105. Other, please specify:

End of Section B

How do I talk to my child about his/her epilepsy? (Section C)

In this section, we are interested in what types of situations and how often you talk to your child about his/her epilepsy.
Please read each statement carefully. Indicate how you feel about each statement.

I usually talk to my child about his/her epilepsy when…

C1. My child has a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C2. My child takes his/her medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C3. My child asks me questions
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C4. My child has a hospital appointment coming up or has recently had a hospital appointment
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C5. My child's medication is causing difficulties
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C6. My child cannot partake in an activity due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C7. My child is worried/upset
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C8. My child needs support
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C9. Other, please specify:

When I talk to my child about his/her epilepsy, what do we talk about?

When I talk to my child about his/her epilepsy, we talk about…

C10. What epilepsy is
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C11. How my child feels about having epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C12. What happens when my child has a seizure (e.g. how he/she appears)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C13. My child's medication
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C14. Medication side effects
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C15. My child's hospital appointments
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C16. Restrictions my child experiences due to his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C17. My child's seizure control (or lack thereof)
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C18. Whether my child will grow out of his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C19. Other, please specify:

Why do I choose to talk to my child about his/her epilepsy?
We are interested in what informs your decision whether to talk to your child about his/her epilepsy or not.

I talk to my child about his/her epilepsy because…

C20. I don't want my child to feel different
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C21. I want my child to know what he/she should do in the event of a seizure
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C22. It helps my child to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C23. It helps me to deal with certain situations
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

I talk to my child about his/her epilepsy because…

C24. I want my child to be informed about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C25. I don't want my child to keep secrets about his/her epilepsy
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I never talk to my child about his/her epilepsy

C26. Other, please specify:

I don't talk to my child about his/her epilepsy because…

C27. I don't want to single my child out in comparison to his/her siblings
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

C28. I don't want to worry my child
☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

C29. I don't want my child to dwell on his/her epilepsy

☐ Really true for me ☐ Sort of true for me ☐ Not at all true for me
☐ Does not apply to me, I always talk to my child about his/her epilepsy

C30. Other, please specify:

What helps or hinders me when talking to my child about his/her epilepsy?

We are interested in what you find helpful or challenging when talking to your child about his/her epilepsy.

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?

C31. My child's disposition (i.e. – your child's temperament and nature)

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C32. The amount of time my child has had epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C33. The level of information I have about my child's epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C34. My child's seizures are well controlled

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C35. Portrayals of epilepsy in the media

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C36. My own attitudes towards epilepsy

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C37. Experiences I had with epilepsy prior to my child's diagnosis

☐ This encourages me ☐ This discourages me
☐ Not applicable, this has no impact on how much I talk to my child about his/her epilepsy

C38. Other, please specify:

What happens when I talk to my child about his/her epilepsy?
We are interested in finding out how talking to your child about his/her epilepsy makes you feel.
Talking about epilepsy with my child makes me feel…

C39. Reassured
☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C40. Optimistic
☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C41. Anxious
☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C42. Uncomfortable
☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C43. Pessimistic
☐ Yes ☐ No ☐ Does not apply, I never talk to my child about his/her epilepsy

C44. Other, please specify:

End of Section C

Section D

In this section we would like to ask you some questions about how you feel about your child's epilepsy
Please indicate how much you *agree or disagree* with each of the following statements.

D1. People, who know that my child has epilepsy, treat him/her differently.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D2. It really doesn't matter what I say to people about my child's epilepsy: they usually have their minds made up.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D3. My child always has to prove him/herself because of the epilepsy.
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D4. Because of the epilepsy, my child will have problems in finding a husband or wife
☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D5. In many people's minds, epilepsy attaches a stigma or a label to my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D6. I know how to recognize side effects or problems from my child's medicine for the epilepsy. *(Please skip if your child is not on medication)*

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D7. I find myself getting irritable with my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D8. I cheer up my child when he/she is sad.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D9. I enjoy staying home with my child more than going out with my friends.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D10. My child talks to me when he/she is afraid.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D11. I am often too tired from dealing with the epilepsy to do the things for fun that I used to do.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D12. I know what to do when the next seizure happens.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D13. We have fewer leisure outings with families since my child developed epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D14. Handling the behaviour of my child is hard for me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D15. My child usually feels better after I talk over worries with him/her.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D16. My partner and I disagree about how to handle the epilepsy.
(*Please skip if you do not have a partner*)

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D17. I am usually successful when I try to get my child to do something.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D18. Despite my best efforts, I am uncomfortable with how my child and I get along.

☐Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D19. I do a good job of disciplining my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D20. I know when to call the doctor about my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D21. My child is overly dependent on me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D22. I am proud of the accomplishments of my child.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D23. Having one child with epilepsy makes it difficult on other children in the family.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D24. Our family activities outside the home are limited because of worry that my child will have a seizure in front of others.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D25. I need to know what my child is doing at all times.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D26. I do a good job of supporting my child in doing things that are hard for him/her.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D27. The only time I am happy is when my child is doing well.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D28. I know when to take my child to the accident/ emergency department for epilepsy

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D29. Our family goes on fewer leisure outings because of my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D30. My partner and I disagree about how to discipline my child because of the epilepsy. *(Please skip if you do not have a partner)*

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D31. I usually understand what my child needs from me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D32. I limit the activities of my child more than our doctor recommends.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D33. I feel confident in my ability to handle my child's epilepsy.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D34. I give more attention to my child than other people in the family.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D35. My child has his/her own feelings and ideas, and it is okay for him/her to tell me about them.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D36. My child is my life's only focus.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D37. I like my child better when he/she does not disturb me.

☐ Strongly Disagree ☐ Agree
☐ Disagree ☐ Strongly Agree
☐ Neither Disagree nor Agree

D38. When I think of myself as a parent of my child, I believe I can handle anything that happens.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

D39. My partner and I have less time to spend together because of my child's epilepsy. ***(Please skip if you do not have a partner)***

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

D40. My partner and I differ about how to tell others about my child's epilepsy. ***(Please skip if you do not have a partner)***

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

End of Section D

Section E

In this section we are interested in how you engage with the people in your life, both within your family and outside it, and how you respond to distressing situations.
Please indicate the extent to which you agree or disagree with the following statements:

E1. When I feel upset, I usually confide in my friends.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E2. I prefer not to talk about my problems.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E3. When something unpleasant happens to me, I often look for someone to talk to.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E4. I typically don't discuss things that upset me.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E5. When I feel depressed or sad, I tend to keep those feelings to myself.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E6. I try to find people to talk with about my problems.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E7. When I am in a bad mood, I talk about it with my friends.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E8. If I have a bad day, the last thing I want to do is talk about it.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E9. I rarely look for people to talk with when I am having a problem.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E10. When I'm distressed I don't tell anyone.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E11. I usually seek out someone to talk to when I am in a bad mood.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E12. I am willing to tell others my distressing thoughts.

☐ Strongly Disagree
☐ Disagree
☐ Neither Disagree nor Agree
☐ Agree
☐ Strongly Agree

E13. There is a special person who is around when I am in need.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E14. There is a special person with whom I can share my joys and sorrows.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E15. My family really tries to help me.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E16. I get the emotional help and support I need from my family.

☐ Very Strongly Disagree
☐ Strongly Disagree
☐ Mildly Disagree
☐ Neither Disagree nor Agree
☐ Mildly Agree
☐ Strongly Agree
☐ Very Strongly Agree

E17. I have a special person who is a real source of comfort to me.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E18. My friends really try to help me.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E19. I can count on my friends when things go wrong.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E20. I can talk about my problems with my family.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E21. I have friends with whom I can share my joys and sorrows.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E22. There is a special person in my life who cares about my feelings.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E23. My family is willing to help me make decisions.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

E24. I can talk about my problems with my friends.

☐ Very Strongly Disagree ☐ Mildly Agree
☐ Strongly Disagree ☐ Strongly Agree
☐ Mildly Disagree ☐ Very Strongly Agree
☐ Neither Disagree nor Agree

End of Section E

Section F

In this section we are interested in learning about how you like to parent your child.
In the following statements, please indicate how often you exhibit this behaviour with your child.

F1. I encourage my child to talk about his/her troubles.

☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F2. **I guide my child by punishment more than by reason.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F3. **I know the names of my child's friends.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F4. **I find it difficult to discipline my child.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F5. **I give praise when my child is good.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F6. **I spank when my child is disobedient.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F7. **I joke and play with my child.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F8. **I withhold scolding or criticism even when my child acts contrary to my wishes.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F9. **I show sympathy when my child is hurt or frustrated.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F10. **I punish by taking privileges away from my child with little if any explanation.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F11. **I spoil my child.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F12. **I give comfort and understanding when my child is upset.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F13. **I yell or shout when my child misbehaves.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F14. **I am easy going and relaxed with my child.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F15. **I allow my child to annoy someone else.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F16. **I tell my child our expectations of behavior before the child engages in an activity.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F17. **I scold and criticize to make my child improve.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F18. **I show patience with my child.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F19. **I grab my child when being disobedient.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F20. **I state punishments to my child and do not actually do them.**
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F21. I am responsive to my child's feelings or needs.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F22. I allow my child to give input into family rules.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F23. I argue with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F24. I appear confident about parenting abilities.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F25. I give my child reasons why rules should be obeyed.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F26. I appear to be more concerned with my own feelings than with my child's feelings.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F27. I tell my child that I appreciate what the child tries or accomplishes.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F28. I punish by putting my child off somewhere alone with little if any explanation.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F29. I help my child to understand the impact of behaviour by encouraging my child to talk about the consequences of own actions.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F30. I am afraid that disciplining my child for misbehaviour will cause the child to not like his/her parent(s).
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F31. I take my child's desires into account before asking the child to do something.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F32. I explode in anger towards my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F33. I am aware of problems or concerns about my child in school.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F34. I threaten my child with punishment more often than actually giving it.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F35. I express affection by hugging, kissing, and holding my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F36. I ignore my child's misbehavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F37. I use physical punishment as a way of disciplining my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F38. I carry out discipline after my child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F39. I apologize to my child when making a mistake in parenting.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F40. I tell my child what to do.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F41. I give into my child when the child causes a commotion about something.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F42. I talk it over and reason with my child when the child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F43. I slap my child when the child misbehaves.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F44. I disagree with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F45. I allow my child to interrupt others.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F46. I have warm and intimate times together with my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F47. When two children are fighting, I discipline the children first and ask questions later.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F48. I encourage my child to freely express himself/herself even when disagreeing with parent(s).
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F49. I bribe my child with rewards to bring about compliance.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F50. I scold or criticize when my child's behavior doesn't meet my expectations.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F51. I show respect for my child's opinions by encouraging my child to express them.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F52. I set strict well-established rules for my child.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F53. I explain to my child how I feel about the child's good and bad behavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F54. I use threats as punishment with little or no justification.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F55. I take into account my child's preferences in making plans for the family.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F56. When my child asks why he/she has to conform, I state: because I said so, or I am your parent and I want you to.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F57. I appear unsure on how to solve my child's misbehavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F58. I explain the consequences of the child's behavior.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F59. I demand that my child does things.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F60. I channel my child's misbehavior into a more acceptable activity.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F61. I shove my child when the child is disobedient.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

F62. I emphasize the reasons for rules.
☐ Never ☐ Once in a While ☐ About Half of the Time ☐ Very Often ☐ Always

End of Section F

The Impact of Epilepsy (Section G)

In this section we would like to ask you some questions about how epilepsy affects your child's and your family's everyday life.

G1. How much extra supervision is needed in your child's daily activities?
☐ None ☐ A little ☐ Some ☐ A lot

G2. Does your child require special precautions in daily activities (such as wearing a helmet)?
☐ Never ☐ Sometimes ☐ Usually ☐ Always

G3. Does the epilepsy influence the freedom of your child to play in the house?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G4. Does epilepsy influence the freedom of your child to play outside?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G5. Does epilepsy influence the freedom of your child to go swimming?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G6. Does epilepsy influence the freedom of your child to participate in sports activities (excluding swimming)?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G7. Does epilepsy influence the freedom of your child in traffic (such as riding a bicycle)?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G8. Does epilepsy influence the freedom of your child to stay elsewhere overnight (with friends or family)?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G9. Does epilepsy influence the freedom of your child to go to parties?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G10. Does epilepsy influence the freedom of your child to participate in physical education?
☐ Not at all ☐ A little ☐ Some ☐ A lot

G11. During the past week, how often did you feel helpless or frightened when your child experienced seizures?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G12. During the past week, how often did your family need to change plans because of your child's epilepsy?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G13. During the past week, how often did you feel frustrated or impatient because your child was irritable due to epilepsy?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G14. During the past week, how often did your child's epilepsy interfere with your job or work around the house?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G15. During the past week, how often did you feel upset because of your child's seizures?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G16. During the past week, how often did you have sleepless nights because of your child's epilepsy?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G17. During the past week, how often were you bothered because your child's epilepsy interfered with family relationships?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G18. During the past week, how often were you awakened during the night because of your child's epilepsy?

☐ All of the time ☐ Once in a while
☐ Most of the time ☐ Hardly any of the time
☐ Quite often ☐ None of the time
☐ Some of the time

G19. During the past week, how often did you feel angry that your child has epilepsy?

☐ All of the time
☐ Most of the time
☐ Quite often
☐ Some of the time
☐ Once in a while
☐ Hardly any of the time
☐ None of the time

G20. During the past week, how worried or concerned were you about your child's performance of normal daily activities?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G21. During the past week, how worried or concerned were you about your child's epilepsy medications and side effects?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G22. During the past week, how worried or concerned were you about being overprotective of your child?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

G23. During the past week, how worried or concerned were you about your child being able to lead a normal life?

☐ Very, very worried or concerned
☐ Very worried or concerned
☐ Fairly worried or concerned
☐ Somewhat worried or concerned
☐ A little worried or concerned
☐ Hardly worried or concerned
☐ Not worried or concerned

In this section, we would like to know how you feel your child's epilepsy affects either your child's or your family's everyday life at the present time and during the past 3 months.

How does epilepsy affect the following areas of your child's or your family's everyday life (social consequences, seizures, and treatment)?

G24. Your child's overall health

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G25. Your child's relationship with parents

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G26. Your child's relationships with siblings

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G27. Your relationship with your spouse/partner

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G28. Your child's relationships with friends/peers

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G29. Your child's acceptability by others

☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G30. Your child's number of activities
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G31. Your child's schooling/academic performance
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G32. Your child's self-esteem
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G33. Your loss of original hopes for your child
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

G34. Family activities
☐ A lot ☐ Some ☐ A little ☐ Not at all ☐ Does not apply

End of Section G

Learning about Epilepsy (Section H)

In this section we would like to ask you some questions about learning about epilepsy. We are interested in the areas where you desire more information about your child's epilepsy or need more help in handling the seizures at this time. At this time…

H1. How much do you need information about seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H2. How much do you need information about treatment of seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H3. How much do you need information about possible causes of seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H4. How much do you need information about handling future seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H5. How much do you need information about any activity restrictions?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H6. How much do you need information about protecting your child from injury?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H7. How much do you need encouragement and support?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H8. How much do you need help in handling responses of others (school personnel, friends, child's peers)?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H9. How much do you need to discuss your concerns and fears about your child's future?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H10. How much do you need to discuss fears about your child's seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H11. How much do you need to discuss concerns about your child's mental health?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H12. How much do you need help with handling your child's response to seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H13. How much do you need for your child to discuss his/her concerns and fears about seizures with other children who have seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

H14. How much do you need for your child to receive counselling about the seizures?
☐ No Need for Information or Help ☐ Strong Need for Information or Help
☐ Some Need for Information or Help

We are also interested in learning about your experiences with doctors and nurses related to the care of your child's epilepsy.
Please respond to the following with the response that best describes how you feel.

H15. The doctors/nurses clearly explained the epilepsy to us
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H16. The doctors/nurses clearly described how the medicine worked, and possible side effects of the medicine prescribed
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H17. The doctors/nurses described any problems from the medicine that would need to be reported immediately
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H18. The doctors/nurses described how to give the medication
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H19. The doctors/nurses gave us an opportunity to ask questions about the seizures
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H20. The doctors/nurses clearly explained what to do in the event of a future seizure
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H21. The doctors/nurses addressed our concerns and fears about seizures
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

H22. The doctors/nurses explained how to handle the seizures at school
☐ Less Than I Wanted ☐ Just As Much As I Wanted ☐ More Than I Wanted

End of Section H

Your Child's Epilepsy (Section I)

In this section we would like to ask you some questions about your child's seizures. Some of the questions will refer to auras or warnings. An aura or warning is a feeling that a child might experience, such as a tummy ache or fuzzy head which might occur on its own, but suggests that a seizure is likely to follow.
Please answer these questions with reference to the seizures your child has experienced in the past year.

I1. Over the past year, how often have your child's seizures consistently occurred at a particular time of day or night?

☐ Always ☐ Sometimes
☐ Usually ☐ Never or can occur at any time of day or night

I2. Over the past year, when your child has had a seizure, how often has he/she been able to tell you when a seizure was going to occur in time to be able to protect him/herself?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I3. Over the past year, how often have you child's seizures occurred during sleep?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I4. Over the past year, how many things that your child wanted to do have been stopped because of seizures?

☐ Almost all things were stopped because of seizures
☐ A lot of things were stopped because of seizures
☐ A few things were stopped because of seizures
☐ Seizures did not stop my child from doing things he or she wanted to do

I5. Has your child passed out (become unconscious or fainted) during seizures over the past year? (If no, mark "Does not or does so for less than 1 minute" and go to the next question. If yes, proceed.)
When your child has passed out during seizures over the past year, how long has it commonly lasted?

☐ Does not or does so for less than 1 minute ☐ Between 2 and 5 minutes
☐ Between 1 and 2 minutes ☐ For more than 5 minutes

I6. Is your child ever confused after seizures? (If no, mark "Not confused at all" and Go to the next question. If yes, proceed.)
Over the past year, how confused has your child commonly been after his/her seizures?

☐ Very confused ☐ Slightly confused
☐ Moderately confused ☐ Not confused at all

I7. During the past year, how often has your child appeared to be sleepy or had a headache after the seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I8. During the past year, how often has your child wet him/herself during a seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I9. During the past year, how often has your child bitten his/her tongue or injured him/herself during a seizure?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I10. In the past year, how long has it usually been before your child could return to what he/she was doing before the seizure?

☐ Immediate return or less than 1 minute ☐ Between 6 minutes and 1 hour
☐ Between 1 and 5 minutes ☐ 1 hour or more

I11. In the past year, how often were you child's seizures extremely disruptive (e.g., shouting, wandering, undressing) to others viewing the seizures?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

I12. During the past year because of seizures, how often did your child need to wear a helmet to protect him/herself?

☐ Always ☐ Sometimes
☐ Usually ☐ Never

End of Section I

END OF QUESTIONNAIRE


DCU
Epilepsy Ireland
Temple Street
CHILDREN'S UNIVERSITY HOSPITAL
HRB
Health Research Board

Appendix L7: Child/Young-Person Resource Sheet (Phase Two)

Child/Young Person Resource List

Thank you so much for taking part in our project! We really appreciate you filling in our questionnaire. If you want to contact us or to find out more about the study, please feel free to contact us by email, if you have your parents' permission:
talkingaboutepilepsy@gmail.com

In case any of the questions made you feel upset in any way, please talk to your parents or feel free to ring the following helplines or look at the following websites with your parents' permission.

- Epilepsy Ireland

  www.epilepsy.ie

  Tel: 01-4557500

- Reach Out

  www.reachout.com

- Headstrong

  www.headstrong.ie

Appendix L8: Parent Resource Sheet (Phase Two)

Parent Resource List

Many thanks again for participating in our research. Your time and contributions are really appreciated. If you wish to contact us or are interested in the findings of the study, please feel free to contact Stephanie on 01-7006867 or Ailbhe on 01-7007997. Alternatively, you can contact us by e-mail: **talkingaboutepilepsy@gmail.com**

In case any of the questions have adversely affected you in any way, please feel free to ring the following helplines or consult the following websites.

- Epilepsy Ireland

  www.epilepsy.ie

  Tel: 01-4557500

- Parent-line

  www.parentline.ie

  Tel: 1890927277

- Aware

  www.aware.ie

  Tel: 1890 303302

We have asked your child to talk to you in case any of the questions made him/her feel upset in any way. Additionally, below is a list of child-friendly resources that you can refer your child to if he/she needs any further support.

- Epilepsy Ireland

  www.epilepsy.ie

  Tel: 01-4557500

- Reach Out

  www.reachout.com

- Headstrong

  www.headstrong.ie

Appendix L9: Recruitment Advertisement (Phase Two)

Talking about Epilepsy

We are trying to find out what it is like for children living with epilepsy and their parents.

Who is involved? Our names our Stephanie O' Toole and Ailbhe Benson and we are PhD students at DCU. We are doing a project in collaboration with Epilepsy Ireland and we are looking for children and young people (aged 8 – 18 years) with a diagnosis of epilepsy as well as their parents to participate.

What will the study involve? The study will involve children and young people and their parents filling out questionnaires.

Why is this study beneficial? This study will help us to learn more about the challenges (positive and negative) that face children living with epilepsy and their parents. Such information will help us to tackle the negative challenges faced by children living with epilepsy in the future and ultimately it will help us to raise awareness about epilepsy in children.

How do we participate? If you are interested in knowing more, or you think you and your child would like to participate, please contact us by phone - 0877538108 (Stephanie) or 0873124218 (Ailbhe) - or by email at talkingaboutepilepsy@gmail.com. Although your participation would be highly appreciated, you do not have to take part - it is completely up to you.

Appendix L10: Two Week Follow-Up Letter (Phase Two)

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 2 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. If you have not yet had the chance to complete the questionnaires, we would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. Again, we would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your engagements with Epilepsy Ireland.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. **Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so.** If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

Kind Regards,

Ailbhe Benson *(PhD student)* Stephanie O' Toole *(PhD student)*

Phone: 01-7007997 ***Phone: 01-7006867***

Appendix L11: Four Week Follow-Up Letter (Phase Two)

Reminder: "Talking about Epilepsy" Research Study

Dear

Approximately 4 weeks ago, you received correspondence from the 'Talking about Epilepsy' research team requesting your participation in a very important questionnaire about how children living with epilepsy and their parents communicate about epilepsy.

If you have already completed and returned the questionnaires, please accept our sincere thanks and appreciation and disregard this letter. We are writing to you again because of the importance each questionnaire has to the usefulness of this study. If you have not yet had the chance to complete the questionnaires, we would encourage you to please do so either in hard copy format or online. In order for the results to truly represent the opinions of all families living with epilepsy, it is important that as many questionnaires as possible are completed and returned. This research is the first of its kind and is highly important in terms of both: (a) highlighting areas for advancement in paediatric epilepsy care in Ireland; and (b) finding ways to enhance public perceptions of epilepsy. Only through your help can the success of this study be ensured. Again, we would like to emphasise that your participation is entirely voluntary and anonymous. Therefore, if you do not wish to participate, please disregard this follow-up letter. This will in no way affect your engagements with Epilepsy Ireland.

If by some chance you did not receive the questionnaire or in the event that your questionnaire has been misplaced and you would still like to participate in the study, please contact a member of the research team by phone or by e-mail (talkingaboutepilepsy@gmail.com) and they will mail you out another one. **Alternatively, if you would like to complete these questionnaires either over the telephone or face-to-face with a member of the research team, we would be happy to call you or arrange a meeting at a time and location of your choice in order to do so.** If you have any further queries about the study, or any suggestions as to how we could make the process as easy as possible for you, please do not hesitate to contact Ailbhe (**01-7007997**) or Stephanie (**01-7006867**), who would be happy to answer any questions and receive any suggestions you might have.

Once again, we would like to extend our gratitude for all of your assistance and support-without the input of families living with epilepsy, this research would not be possible.

Kind Regards,

Ailbhe Benson *(PhD student)* Stephanie O' Toole *(PhD student)*

Phone: 01-7007997 ***Phone: 01-7006867***

Appendix M: Tests of Normality

Appendix M1: Tests of Normality (CWE Data)

CWE-reported Variables			
Parent-Child Communication Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
Mother-Child Communication Level	-.1.686	No	Spearman's Correlation
Father-Child Communication Level	-1.208	No	Spearman's Correlation
Positive Affect of Communication	-0.136	Yes	Pearson's Correlation
Negative Affect of Communication	1.163	No	Spearman's Correlation
Socio-Orientation	0.135	Yes	Pearson's Correlation
Concept Orientation	0.779	Yes	Pearson's Correlation
Demographic Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Age	-0.350	Yes	Pearson's Correlation
CWE Gender	-0.132	Yes	Independent t-test
Clinical Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Seizure Type			
Tonic-Clonic	-0.046	Yes	Independent t-test
Absence	0.732	Yes	Independent t-test
Simple Partial	-1.744	No	Mann Whitney U
Complex Partial	-1.231	No	Mann Whitney U
Myoclonic	-1.383	No	Mann Whitney U
Atonic	-4.575	No	Mann Whitney U
Tonic	-2.990	No	Mann Whitney U
Clonic	-2.561	No	Mann Whitney U
ESES	-6.708	No	Mann Whitney U
Seizure Visibility	1.894	No	Mann Whitney U
Seizure Frequency	-0.842	Yes	Pearson's Correlation
Psychosocial Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Stigma	0.710	Yes	Pearson's Correlation
CWE Illness Attitudes	-0.057	Yes	Pearson's Correlation
CWE Self-Perception	-0.480	Yes	Pearson's Correlation
Scholastic Competence	0.192	Yes	Pearson's Correlation
Social Competence	-0.494	Yes	Pearson's Correlation
Athletic Competence	-0.420	Yes	Pearson's Correlation
Physical Appearance	-0.386	Yes	Pearson's Correlation
Behavioural Conduct	-0.326	Yes	Pearson's Correlation
Global Self-Worth	-0.790	Yes	Pearson's Correlation
CWE Health-related Quality of Life	-0.306	Yes	Pearson's Correlation
Interpersonal Social Consequences	-1.165	No	Spearman's Correlation
Worries and Concerns	0.045	Yes	Pearson's Correlation
Intrapersonal Emotional Issues	-0.143	Yes	Pearson's Correlation
Epilepsy my Secret	-0.164	Yes	Pearson's Correlation
Quest for Normality	-0.648	Yes	Pearson's Correlation

Appendix M1: Tests of Normality (CWE Data) (continued)

Psychosocial Variables *(continued)*	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Perceived Social Support	-0.842	Yes	Pearson's Correlation
Parental Support	-1.584	No	Spearman's Correlation
Classmate Support	-1.037	No	Spearman's Correlation
Teacher Support	-0.602	Yes	Pearson's Correlation
Close Friend Support	-1.708	No	Spearman's Correlation
CWE Need for Info and Support	-0.088	Yes	Pearson's Correlation
Need for Information	0.282	Yes	Pearson's Correlation
Need for Support	-0.658	Yes	Pearson's Correlation
CWE Satisfaction with Info Received	-0.669	Yes	Pearson's Correlation

Appendix M2: Tests of Normality (Parent Data – Whole Sample)

Parent-Child Communication Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
Parent-Child Communication Level	-1.070	No	Spearman's Correlation
Authoritative Style	-0.410	Yes	Pearson's Correlation
Authoritarian Style	0.488	Yes	Pearson's Correlation
Permissive Style	0.339	Yes	Pearson's Correlation
Demographic Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Age	-0.220	Yes	Pearson's Correlation
CWE Gender	0.092	Yes	Independent t-test
Parent Age	-0.966	Yes	Pearson's Correlation
Parent Gender	3.052	No	Mann Whitney U
Parent Education Level	0.530	Yes	Pearson's Correlation
Clinical Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
CWE Seizure Type			
Tonic-Clonic	0.286	Yes	Independent t-test
Absence	0.345	Yes	Independent t-test
Simple Partial	-1.365	No	Mann Whitney U
Complex Partial	-0.656	Yes	Independent t-test
Myoclonic	-1.365	No	Mann Whitney U
Atonic	-2.316	No	Mann Whitney U
Tonic	-2.133	No	Mann Whitney U
Clonic	-1.365	No	Mann Whitney U
ESES	-8.485	No	Mann Whitney U
Seizure Visibility	1.577	No	Mann Whitney U
Family History of Epilepsy	0.125	Yes	Independent t-test
Seizure Frequency	-0.883	Yes	Pearson's Correlation
Seizure Severity	0.055	Yes	Pearson's Correlation
Psychosocial Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
Parent Stigma	0.319	Yes	Pearson's Correlation
Parent Response to Child Illness	-0.198	Yes	Pearson's Correlation
Child Support	-0.154	Yes	Pearson's Correlation
Family Life and Leisure	-0.678	Yes	Pearson's Correlation
Condition Management	-0.309	Yes	Pearson's Correlation
Child Autonomy	-0.589	Yes	Pearson's Correlation
Child Discipline	-0.519	Yes	Pearson's Correlation
Perceived Impact of Epilepsy on Family	0.693	Yes	Pearson's Correlation
Perceived Impact of Epilepsy on CWE	0.815	Yes	Pearson's Correlation
Parent Perceived Social Support	-0.848	Yes	Pearson's Correlation
Significant Other Support	-0.889	Yes	Pearson's Correlation
Family Support	-1.199	No	Spearman's Correlation
Friends Support	-1.060	No	Spearman's Correlation
Parent Need for Info and Help	0.705	Yes	Pearson's Correlation
Need for Information	1.076	No	Spearman's Correlation
Need for Help	0.202	Yes	Pearson's Correlation
Parent Satisfaction with Info Received	-0.788	Yes	Pearson's Correlation

Appendix M3: Tests of Normality (Parent Data –Dyadic Sample)

Parent-Child Communication Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
Parent-Child Communication Level	-1.418	No	Spearman's Correlation
Authoritative Style	-0.560	Yes	Pearson's Correlation
Authoritarian Style	0.777	Yes	Pearson's Correlation
Permissive Style	0.510	Yes	Pearson's Correlation
Psychosocial Variables	**Skewness Statistic**	**Normality Assumed**	**Analysis to be Performed**
Parent Stigma	0.630	Yes	Pearson's Correlation
Parent Response to Child Illness	-0.306	Yes	Pearson's Correlation
Child Support	-0.331	Yes	Pearson's Correlation
Family Life and Leisure	-1.023	No	Spearman's Correlation
Condition Management	-0.702	Yes	Pearson's Correlation
Child Autonomy	-0.503	Yes	Pearson's Correlation
Child Discipline	-0.549	Yes	Pearson's Correlation
Perceived Impact of Epilepsy on Family	0.935	Yes	Pearson's Correlation
Perceived Impact of Epilepsy on CWE	1.027	No	Spearman's Correlation
Parent Perceived Social Support	-0.975	Yes	Pearson's Correlation
Significant Other Support	-0.871	Yes	Pearson's Correlation
Family Support	-1.099	No	Spearman's Correlation
Friends Support	-0.918	Yes	Pearson's Correlation
Parent Need for Info and Help	0.667	Yes	Pearson's Correlation
Need for Information	0.822	Yes	Pearson's Correlation
Need for Help	0.465	Yes	Pearson's Correlation
Parent Satisfaction with Info Received	-0.945	Yes	Pearson's Correlation

Appendix N: Research Dissemination

Appendix N1: Publications

- **O'Toole, S.,** Benson, A., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). Family communication in the context of pediatric epilepsy: A systematic review. *Epilepsy & Behavior, 51,* 225-239.
- **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). Talking about epilepsy: Challenges parents face when communicating with their child about epilepsy and epilepsy-related issues. *Epilepsy & Behavior, 57,* 9-15.
- **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). *"I don't like talking about it because that's not who I am"*: Challenges children face during epilepsy-related family communication. *Chronic Illness, 12,* 216 – 226.
- Benson, A., **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents. *Epilepsy & Behavior, 51,* 73-95.
- Lambert, V., Gallagher, P., **O'Toole, S.**, & Benson, A. (2014). Stigmatising feelings and disclosure apprehension among children with epilepsy. *Nursing Children and Young People, 26,* 22-26.
- Benson, A., **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). The stigma experiences and perceptions of families living with epilepsy: Implications for epilepsy-related communication within and external to the family unit. *Patient Education and Counseling, 99*(9), 1473-1481.

Appendix N2: Conference Proceedings

- **O'Toole S.**, Benson, A., Lambert V., Gallagher, P., Shahwan A. & Austin, J.K. (2015). *Feeling under-informed: Parental challenges when communicating about epilepsy.* International Conference on Communication in Healthcare (ICCH), New Orleans, U.S., October 2015 *(oral presentation).*
- Benson, A., **O'Toole, S.**, Lambert V., Gallagher P., Shahwan, A. & Austin, J.K. (2015). *The lived stigma experiences of families living with epilepsy: Implications for familial engagement in dialogue surrounding the condition.* International Conference on Communication in Healthcare (ICCH), New Orleans, U.S., October 2015 *(oral presentation).*
- **O'Toole, S.**, Benson, A., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *Familial interactions about epilepsy: The perspectives of children living with epilepsy and their parents.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 2015 *(oral presentation).*
- **O'Toole, S.**, Benson, A., Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *Child and parent perspectives of navigating the education system with a diagnosis of childhood epilepsy.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 2015 *(oral presentation).*
- Benson, A., **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *Concealable stigmatized identity revelations: Familial experiences of telling or not telling other about a child's epilepsy diagnosis.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 2015 *(oral presentation).*
- Benson, A., **O'Toole, S.**, Lambert, V., Gallagher, P., Shahwan, A. & Austin, J.K. (2015). *The stigma experiences of children living with epilepsy and their parents: A hidden condition.* 21st Qualitative Health Research (QHR) Conference, Toronto, Canada, October 2015 *(oral presentation).*
- **O' Toole, S.**, Lambert V, Shahwan A, Gallagher P. *Demystify the veil of secrecy: A mixed method inquiry of parent-child dialogue about epilepsy and its associated stigma.* Staff and Graduate Student Expo, School of Nursing and Human Sciences, Dublin City University, Ireland, April 2015 *(poster presentation).*

Appendix N2: Conference Proceedings (continued)

- **O'Toole, S.**, Benson, A., Lambert, V., Shahwan, A. & Gallagher, P. (2015). *Epilepsy as a concealable stigmatised identity: Challenges families face when communicating about and disclosing a diagnosis of epilepsy in childhood.* Joint Neurological Alliance of Ireland and Irish Brain Council Conference, Trinity College Dublin, Ireland, March 2015 *(poster presentation).*
- Benson, A., **O'Toole, S.**, Lambert, V., Shahwan, A. & Gallagher, P. (2015). *Parent narratives of communication with healthcare professionals at the time point of diagnosis of their child's epilepsy.* Joint Neurological Alliance of Ireland and Irish Brain Council Conference, Trinity College Dublin, Ireland, March 2015 *(poster presentation).*
- **O'Toole, S.**, Benson, A., Lambert, V., Gallagher, P. & Shahwan, A. (2014). *Living with a concealable stigmatizing identity: The experiences of children living with epilepsy and their parents.* Children's Research Network (CRN) Annual Conference, Dublin, Ireland, December 2014 *(oral presentation).*
- Benson, A., **O'Toole, S.**, Lambert, V., Gallagher, P. & Shahwan, A. (2014). *Navigating the Irish education system with a diagnosis of epilepsy in childhood: Child and parent perspectives.* Children's Research Network (CRN) Annual Conference, Dublin, Ireland, December 2014 *(oral presentation).*
- **O' Toole, S.**, Lambert, V., Shahwan, A. & Gallagher P (2014). *Communication avoidance: Parent and child perspectives on the challenges families face when talking about epilepsy.* EACH (European Association of Communication in Healthcare) International Conference on Communication in Healthcare, Amsterdam, Netherlands, September 2014 *(oral presentation).*
- **O'Toole, S.**, Benson, A., Lambert, V., Shahwan, A. & Gallagher P. (2014). *Communication at the time point of childhood diagnosis of epilepsy: Parents' perspectives.* EACH (European Association of Communication in Healthcare) International Conference on Communication in Healthcare, Amsterdam, Netherlands, September 2014 *(poster presentation).*
- **O'Toole, S.**, Lambert, V., Shahwan, A. & Gallagher, P. (2014). *Communication in families living with childhood epilepsy: Hyper-vigilance and the restriction of social activities.* European Health Psychology Society (EHPS) Conference, Innsbruck, Austria, August 2014 *(poster presentation).*

Appendix N2: Conference Proceedings (continued)

- Benson, A., **O'Toole, S.**, Lambert, V., Shahwan, A. & Gallagher P. (2014). *The cycle of invisibility: Implications for family communication and the selection of disclosure strategies in families living with epilepsy.* European Health Psychology Society (EHPS) Conference, Innsbruck, Austria, August 2014 *(poster presentation).*
- **O' Toole, S.**, Lambert, V., Shahwan, A. & Gallagher, P. (2014). *Talking about epilepsy: Parent-child dialogue in families living with childhood epilepsy.* Children's Research Network (CRN) PhD Symposium, University College Dublin, Ireland, August 2014 *(oral presentation).*
- **O' Toole, S.**, Lambert, V., Shahwan, A. & Gallagher, P. (2013). *Families talking about epilepsy: a parent and child perspective.* Health Research in a Changing Environment, Medical Research Charities Group Research Conference, Rotunda Hospital, Dublin, Ireland, November 2013 *(poster presentation).*
- **O' Toole, S.**, Lambert, V., Gallagher, P. & Shahwan A. (2013). *A qualitative exploratory study of the impact that parents perceptions of epilepsy and its associated stigma might have on children's perceptions of their epilepsy and its associated stigma.* The Psychological Society of Ireland 43rd Annual Conference, Sligo, Ireland, November 2013 *(poster presentation).*
- **O' Toole, S.**, Lambert, V., Shahwan, A. & Gallagher P. (2013). *Family Conversations about Epilepsy; A Parent and Child Perspective.* 13th European Conference on Epilepsy and Society, Ljubljana, Slovenia, August 2013 *(poster presentation).*